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Redefining the Experience of Raising a Child with Disabilities in Tajikistan

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by

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Abstract

This dissertation explores the relationship between empowerment and social capital formation among mothers of children with disabilities in Tajikistan as a result of their participation in parent associations. Mothers of children with disabilities in Tajikistan face extreme social stigma because of traditional beliefs that their child's disability is a reflection of their own sinful behavior. This results in a wide variety of overt discrimination for both mother and child. This can include institutionalization of children from birth, withholding medical care at birth or in early childhood, purposefully mislabeling a disability as "birth trauma" in hopes of protecting the mother, and hiding children with disabilities at home. For the mother, consequences can include limited marriage prospects for her other children, divorce, significantly reduced social status, and outright abuse within her marriage family or her birth family if she is forced to return to them following a divorce. The Soviet legacy of defectology reinforces this marginalization by framing disability as a defect within the child that requires correction through specialized services and segregated schooling in order for later participation or inclusion in broader society. Furthermore, formal public provision of specialized services in Tajikistan has largely disintegrated in the economic deprivation following the disintegration of the Soviet Union and the chaos of the civil war.

Within this context civil society organizations concerned with women's health and international organizations, including the Open Society Foundations, have sought to provide support for mothers of children with disabilities. In hopes of helping them through post-partum depression and the psychological pain of isolation, they have supported group therapy and self-help groups. Several of these support groups, some with support from the Open Society Foundations, formed associations of parents of children with disabilities in 2007-13 and then a national Coalition of associations in 2014. The original goal of the association was to continue to support parents psychologically but also to provide services, like physical or occupational therapy, for children. It has also enabled parents to learn as much as possible about their children's disability, collecting or pooling resources to purchase equipment, and developing community-based service delivery. When little is available publicly and services are created from scratch, there is significant space for innovation, which can be a great advantage. However, this also requires a great deal of motivation, self-confidence, and assertiveness from the initial group of participants to develop these models and continued outreach to the community to ensure their sustainability. Together at the national level and individually within their own communities, they advocate for access to education, healthcare, and social benefits as well as working to create a more positive view of disability among the general public.

In the face of such huge barriers that include social stigma, discrimination within their own families, poverty, and lack of services, **how have these women become empowered advocates for themselves and their children?** This research develops three cases studies of parent groups in different parts of Tajikistan (Dushanbe, Khujand, Bokhtar) and with varying profiles (autism, general disability) in addressing this central research question. Building on the literature on empowerment and social capital formation in the fields of community psychology and international development, this

dissertation explores the relationship between empowerment and social capital that grows from crisis or need to gaining knowledge through support from others. The objective is examine whether and how such partnerships, in turn, lead to increased confidence among women and a desire to work together in support of others, while nurturing a growing feeling of self-worth and self-efficacy.

The three cases were developed using qualitative research methods, including interviews and focus groups with association members and key informants, observations of activities within the parent groups, and analysis of documents produced by the groups. Field research was conducted during the summer of 2015. Common themes that emerge from these cases include the challenges of organizational development, especially maintaining the spirit of a parent association as the founding mothers become increasingly professional in their approaches to service delivery, the importance of public events in addressing the stigma associated with disability, and a strong desire to include children with disabilities in broader society through education. Although all public services are important, education is most likely to be available in every community through local schools. It is also likely to be one of the more difficult for children with disabilities to access because of the Soviet legacy of education segregated by disability type. In Tajikistan, the special education system is not readily accessible because there are few schools in operation. Yet in local schools, teachers have little or no training in inclusive education and do not feel prepared to include children with disabilities in their classrooms. This point of interaction between parent and teacher, family and school is a critical test of the parent association's ability not only to advocate for access but to develop the relationships and provide the support to make access meaningful and sustainable.

This research contributes to several bodies of literature. Although there is an existing literature on social capital formation among parents of children with disabilities, most studies focus on North America or Western Europe. Tajikistan is a severely under-researched geography, but even in the broader context of developing world similar studies are rare. In addition, this research brings together literature in fields that include community psychology, social work, political science and development studies, and sociology to develop a cross-disciplinary model of empowerment. Finally, this dissertation contributes to research on civil society development and participation by focusing on the phenomenological relationship between social capital formation and empowerment through participation in formal (registered NGOs) and informal associations.

About the author: Kate Lapham is the deputy director of the Education Support Program of the Open Society Foundations. Her work is focused on overcoming barriers to education for communities facing exclusion or discrimination. Based in New York, Lapham has worked with communities, civil society groups, and education policymakers in the Caucasus, Central Asia, Central and Eastern Europe, and Mongolia and Russia for more than 15 years. She previously worked with IREX, a nonprofit organization dedicated to building quality education, independent media, and strong civil society. Lapham has developed initiatives to strengthen civil society through research for evidence-based advocacy, support for organizational development among young or small NGOs, and direct work with teachers and schools. Her publications include *Learning to See Invisible Children: Inclusion of*

Children with Disabilities in Central Asia. Lapham holds an MPA from Columbia University's School of International and Public Affairs and a BS in foreign service from Georgetown University.

Chapter 1 : Introduction

Disability in Tajikistan is a layered phenomenon. It is tied to family structure, gender relations, the nature of God and religious belief, and the legacy of medical models of disability embedded in the Soviet public health and education systems. Women who give birth to children with disabilities face stigma in the community at large and within their own families from to a variety of converging cultural norms. Yet, there is a growing movement of parents of children with disabilities coming together to support each other and advocate for the rights of their children. This movement raises a number of questions about the ways that these parents, mostly mothers, are able to overcome or subvert cultural norms to work together in the interests of their children.

The current form of this movement is a national Coalition of Associations of Parents of Disabled Children. The coalition began with initiative groups set up by the NGO's "*Zdoroviye*," in Dushanbe (meaning health in Russian) and *Rangikamon* in Khujand to help parents of children with disabilities support each other emotionally and practically as they navigated the systems of education, health, and social services with their children. The groups grew quickly and began supporting like-minded NGOs and initiative groups in other parts of Tajikistan.

Mutual support and empowerment of parents was one of the foundational goals of these parent associations (Whitsel & Kodirov, 2013). As such, it is important to consider the ways and extent to which their work has affected the empowerment of the parents and other caregivers who participate in their activities and to consider how empowerment could be defined in the context of Tajikistan. This research seeks to determine whether and how the associations have empowered parents in their evolution from informal gatherings to more or less sustainable organizations capable of surviving, and more importantly, developing their mission in response to emergent needs and ideas of their members, and finally to a formal coalition bringing together 31 parent groups across the country. This requires

understanding how mothers of children with disabilities are able to emerge from their families, accept and publicly acknowledge their children, and engage in collective action to meet their needs either through initiatives aimed at the creation of services or advocacy for inclusion in existing services. More specifically, it seeks to answer the following questions:

1. Under what circumstances do mothers of children with disabilities in Tajikistan decide to engage in collective action to support their children?
    a. How do the connections between the mothers evolve over time in the different geographical and organizational settings of the three cases?
    b. From the perspective of mothers of children with disabilities, what type of experiences empower them to take collective action?
2. What types of initiatives, in particular in education, are emerging from the parent groups in the three cases?
    a. When and how do they emerge? To what extent are they internally or externally driven and supported?
    b. From the perspective of mothers of children with disabilities, how do these initiatives affect their situation within their extended families and/or communities?

This study builds three case studies from the context of personal and professional experience, illustrating the challenges of raising a child with a disability in Tajikistan, exploring the changes that take place when social capital is built through participation in parent groups. It is a story about power structures within the family, within society, and governing disability. Through the lens of parenting a child with disabilities, we explore what it means to be a mother. By looking at the movement these

mothers have created, we can explore what it means to be an empowered, active citizen. Telling this story requires a contextual portrait of family and motherhood, disability, and civil society in Tajikistan.[1]

Family and motherhood

Mothers of children with disabilities in Tajikistan have particularly reduced agency regarding their children's participation in the family and the wider community through both formal and informal opportunity structures. Norms of family structure and gender already limit the opportunities for young women to participate in decision-making. For example, Harris (2004) explains:

> The decades of Soviet rule produced major and often positive changes at all levels in both the lifestyle and the outlook of Tajik women (and men). Nevertheless, the underlying gender identities that privilege male control and allow elders complete power of decision over their children's fate appear not to have changed much over the last 50 or even 100 years, although they are expressed somewhat differently. (Harris, 2004, p. 65)

These limits tighten further for participants in this study because Tajik cultural norms place shame and stigma on families of children with disability. Folk belief convinces some that disabilities or atypical development are the result of the birth mother engaging in antisocial behavior. As a result, the community often sees a child disabled from birth as 'evidence' of such behavior. The community also may conclude that the men in the child's family have lost control of the birth mother – a significant loss of face and threat to family honor (Gatling & Juraeva, 2013). As a result, parents may have strong social incentives to hide away their children with disabilities (OECD, 2009). The head of the family, typically the oldest male relative, makes decisions and carries considerable authority. If this person decides that having a child with disabilities in the family is shameful, then there is little opportunity

[1] Please refer to Appendix 2 for basic information about Tajikistan. An excellent source for deeper reading is Nourzhanov, K., & Bleuer, C. (2013). *Tajikistan: A political and social history*. ANU E Press.

for that child to participate in family or community life. There is also little room for the mother to increase her status to advocate for the child with disabilities or for her other children.

However, Harris (2004) and her research on gender relations provide some interesting insights into the way the profile of an empowered, civically engaged mother might develop in Tajikistan. When discussing marriage, for example, she finds that "the differing capacities young people have to stand up to their parents …depends on the social status of the individual families and especially on the father's level of self-assurance" (Harris, 2004, p. 127). This means that young women who have recourse to a self-assured family leader or are members of high status families will have increased opportunity to publicly support or advocate for a child with disabilities. She has also found that (especially elder) daughters are able to participate in decision-making when the men in the family are absent (Harris, 2004, pp. 103). As labor migration increasingly removes men from families for long periods of time, or even permanently, women are empowered by necessity to make decisions affecting the family as a whole.[2]

Disability and Society

There are three conceptual models of disability that provide important intellectual context for the theoretical framework in Chapter 2 and the presentation of research that follows: the medical model, the social model, and the political model. The medical model of disability places disability wholly within an individual, seeing a series of impairments or deficiencies that are subject to correction or rehabilitation (Bingham et al., 2013; Marks, 2000; Mitra, 2006). This model can conflate disability and sickness, casting the person with disabilities in the role of patient (LoBianco & Sheppard-Jones, 2008; Marks, 2000; Mitra, 2006; Turnbull & Stowe, 2001). Further, disability becomes the primary identity

[2] In 2013, the World Bank estimated that up to 50% of GDP came from the remittances of labor migrants. Remittances also made up the largest source of Tajikistan's foreign exchange earnings (World Bank, 2014). While exact figures are difficult to find, these economic indicators illustrate the significance of high levels of labor migration for Tajikistan.

of the individual with a disability, shaping the way that others understand and interact with him/her (Haegele & Hodge, 2016).

The social model of disability, developed by Oliver (1986; 1996) contends that disability is the interaction of an individual's characteristics and social structures. In this model, impairment can exist without disability if society refuses to impose the disability label or exclude the individual on the basis of his/her impairment (Goodley, 2001; Roush & Sharby, 2011). The Convention on the Rights of Persons with Disabilities (2006) recognizes the social model in its preamble: "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." This gives rise to the understanding that it is society that must change rather than the person with the disability. This understanding is sufficient for civil rights movements where people with disabilities demand that society change so that they can realize their rights. However, the social model is not by itself a political theory of disability.

A political theory of disability requires an analysis of power and oppression related to disability in the same ways that race and gender studies have done. Abberley (1987) makes this argument effectively.

> To claim that disabled people are oppressed … is to argue at an empirical level that on significant dimensions disabled people can be regarded as a group whose members are in an inferior position to other members of society because they are disabled people. It is also to argue that the disadvantages are dialectically related to an ideology or group of ideologies which justify and perpetuate this situation. Beyond this it is to make the claim that such disadvantages and their supporting ideologies are neither natural nor inevitable. Finally it involves the identification of some beneficiary of this state of affairs. (Abberley, 1987, p.7)

In Chapter 2, we will touch on the idea of critical awareness that Abberley suggests as one of the fundamental elements of empowerment. It is important here to understand the foundations of each

of these models of disability as we explore the realities on the ground that members of parent associations experience.

Disability in Central Asia

Multiple layers of prejudice affect children with disabilities in Central Asia (Katsui, 2005), including both public and private attitudes toward disability that affect the child and the rest of the family. In some sense this prejudice is acute in this region but not necessarily unique to Tajikistan, Central Asia, or the post-Soviet space. The rest of the world has a long and shameful history of discriminating against people with disabilities that is only beginning to be addressed through human rights frameworks and activist movements (McCammon, Spencer, & Friesen, 2001).

However, many of the norms and ideas about disability perpetuated by the legacy of defectology are also strongly rooted in Tajikistan's historical and cultural history as part of the Islamic world with strong cultural links to the historical Persian Empire. Examples of this cultural heritage and connection can be found in Tajik language, which is the only language of the region that is Persian rather than Turkic. The medieval centers of learning in Bukhara and Samarkand, now just across the border in present-day Uzbekistan are culturally Tajik. Both were important hubs of scholarship and commerce from the Soghdian Empire through the 19th century. Thus, research on attitudes toward disability in Islam and the Middle East, particularly Persia / Iran, are culturally relevant to Tajikistan.

Furthermore, most Central Asians, including Tajiks, belong to the Hanafi Sunni sect, which does not have formal clergy or an established leader, which means that the Soviet government found it extremely difficult to uproot or counteract (Harris, 2004, p. 50). This means that a parallel understanding of disability in religious terms would have been left largely unchallenged, in particular where it intersected with Soviet views of disability in a way that may have been mutually reinforcing.

Ghaly (2005) explores the richness and shifts of discussion on disability in the Islamic world with religious scholarship overtaking literary treatments in the 1450s and debates among scholars

continuing into the present. In the texts cited there is a divided presentation of disability as a sign of extra abilities or favor (especially blindness) and as a sign of displeasure from God or the Prophet (Ghaly, 2005). For example, other disabilities, in particular intellectual disabilities and epilepsy, are seen as inflicted by evil spirits (Ghaly, 2008). In both cases, disabilities were characterized as deficits that could and should be cured (Ghaly, 2008; Morad, Nasri, & Merrick, 2001). Within this cultural context, there can be significant stigma associated with disability, which, in the absence of 'rehabilitation', is seen as an immutable incompleteness of a person (Moghaddam, Taylor, & Wright, 1993).

As a result, acknowledging a disability within the family can be profoundly shameful. Brown (2005) cites the findings of researchers in the Middle East that parents often believe a disability is a punishment from God (p. 274). Samadi, McConkey, and Kelly (2013) also report stigma attached to having a family member with intellectual disabilities in Iran, Tajikistan's cultural neighbor. Furthermore, the birth of a child with disabilities is considered by many religious Iranians to be a result of a sin so that disability is a source of shame for the broader family, with negative effects on the marriage prospects of siblings (Samadi, 2008), a view echoed in other research specific to Tajikistan (Gatling & Juraeva, 2013). Katsui (2005) finds that Slavic families in Central Asia are more likely to institutionalize children with disabilities. He attributes this to verses in the Koran that require families to care for those with disabilities. However, this could be a result of greater shame in non-Slavic families preventing them from reaching out to existing services.

Within Islam as well as local communities, the cultural values of compassion, justice, equality, kindness, generosity, and the acceptance of fate as God's will are often prevalent. These can sometimes act as supporting factors for the family. However, they do not completely, or even sufficiently, neutralize the threat to family honor contained in the diagnosis of a disability (Brown, 2005, p. 270). Furthermore, in contrast to Islamic norms, in old Persia, people with intellectual disabilities in

particular were sent off into mountains, forests, and deserts to survive as best they could (Samadi, 2008) rather than remaining a source of shame or a burden to their families – an even more severe fate than isolation or institutionalization.

Katsui (2005) finds similar prejudice within the families of children with disability in other parts of Central Asia which can lead to the isolation of the person with a disability and to hiding children with disabilities from the community. It can also lead to drastic consequences for the mother of a child with disabilities, including abandonment by her husband (Katsui, 2005). It can limit the marriage prospects for the rest of the children in the family, particularly if the oldest daughter has a disability. Tradition dictates that she should marry before younger siblings, but a match may not be possible (Katsui, 2005) which effectively erects a barrier to her sisters' betrothal.

Gatling and Juraeva (2013) further find in Tajikistan that "many traditionally minded Tajiks maintain a folk belief that congenital abnormalities are the result of the birth mother engaging in sexual relations outside of marriage or other behavior considered 'antisocial.' Thus the community often sees a child disabled from birth as 'evidence' of such behavior. The community also often concludes that the males in the child's family have lost control of the birth mother at the expense of their honor" (Gatling & Juraeva, 2013, p. 24). This is a very serious loss of honor for the entire family that is seen to be deserved by the community in a context where fidelity in marriage and bearing healthy children are two of the most important fulfillments of social norms for women (Harris, 2004, pp. 86-87).

One mother who gave birth to a daughter with Down Syndrome eloquently recounts the shame and hopelessness that she felt in the maternity hospital, underlining the importance of support from her husband:

> It's hard because from birth they told me the details of this diagnosis. I didn't know what Down Syndrome was, or the 'illness' Down Syndrome, as they said. I didn't understand what caused it or how to treat it. I suffered with the question of why this happened. In our culture, in our traditions, the reason is that you have committed some kind of sin. That is our mentality and unfortunately I also thought about this. I looked for where or how I might have sinned.

As far as I knew, I had never offended anyone. That idea made me suffer for a long time. Why have I always done everything for everyone but God has punished me in this way? What am I guilty of? And all the time, I was having girls. I gave birth to four girls. Now I don't think about that, but before I did. Why don't I have a boy? We have a big family and I wanted to have one boy at least, and then I had another girl and a disabled one at that. I was offended. Why did this happen?

When they told me, it was so difficult to understand. I had the three girls and they were healthy. Sometimes there were conversations between the families about me having three girls, and no boys. I wondered what would happen this time. If they know that I have given birth to a daughter with Down Syndrome, they will point their fingers at me all the time. That idea made me suffer a lot. I thought about it all night until morning. Then I thought about what would happen to my daughters. They love their father. What if our family falls apart? I decided that I should throw myself and my daughter out the window so that the rest could be happy. [crying] I am not sorry that I did not do that. Instead I am happy to see how she grows up, how she talks and learns. But at that moment, there was a completely different way of life in my head. I wanted to throw myself from the window. But then I thought about my mother and my daughters – what would they do? [crying]

At that moment, the phone rang. It was in the pocket of my robe. It turns out that my husband was also thinking all night. He was standing in the courtyard and couldn't understand why I was standing in the window. He asked what I was doing, wouldn't the baby catch cold? He was standing there and I didn't see him because my thoughts were elsewhere. He told me to get away from the window. I told him that I didn't want to live. He told me to hang on (*mepnu*), I will come to you. He came and calmed me down. He said that whatever God has given, we are going to raise and together we are going to help her. That helped me because at least he was with me. I felt that I had fallen down a deep well and someone had told me to climb out. At that moment, my husband was the rope to climb out. My mother celebrated and threw the traditional party. She was supporting me as a daughter to keep my spirits up because I had another girl. My mother knew something was wrong. She called my cousins because some of them are doctors. As though they didn't know, but they knew and the whole time tried to keep me from dwelling on it. They really helped me and after three years, I feel independent and can cope on my own.

They all protected me, even my husband. But no one protected my husband. He was alone and people did not understand him. I understood how much he suffered. His hair turned gray. Support from my family was the most important thing to keep me going. I was lost. My husband didn't want to tell [his parents and relatives who live outside Dushanbe]. He said let's not tell them. They can see her, but we won't say anything. They knew that something might be wrong but did not know what. They asked in the beginning, but I didn't say anything because my husband said not to. With time, they found out and they are fine because they see

> how she is developing. At the time, they would not have understood. My husband, knowing his family, said not to tell them, let time show them.

This shame and stigma thus isolates families as well as children stopping them from reaching out to others or looking for support. This in turn leads to a poor understanding of what may be possible for children with disabilities. Because ability is viewed as fixed in both the Islamic and Soviet frameworks of disability, expectations for people with disabilities are low. Enjoyment of life through participation in daily activities is seen as impossible in Central Asia. The person with a disability is seen as a helpless person having at best a right to food and basic care but not to participation (Katsui, 2005). This is, in turn, further reinforced in the language of modernity and science by defectology's focus on medical assessments and the things that people with disabilities cannot do (Ahuja & Pirzado, 2006). Furthermore, Harris (2004) finds that high rates of infant mortality, particularly before the advent of Soviet healthcare, contributed to views of children with disabilities as expendable or worth less than other children. For example, she reports the following from an interview with a young mother:

> Zora's mother, who herself had had nine children, when she felt that her daughter was expending an inordinate amount of time and energy caring for her sickly young son [told her to] just let him die [because] you can easily have another who might be stronger. Zora was shocked by this. She loved her son and did not feel he was so easily replaceable; besides she did not want to undergo another pregnancy. (Harris, 2004, p. 110)

In Central Asia, the movement to contribute to the empowerment of children with disabilities is in its infancy. There is hope in Zora's resistance to her mother's advice, and Katsui (2005) finds that there are some examples of parents who try to advocate for their children with disabilities and change public perceptions. On the other hand, Katsui (2005) characterizes parents in Central Asia as passive due to the legacy of the Soviet Union and the social prejudice against disability. Therefore, as a result, "exceptional parents" are a minority who face an uphill battle against a heavily discriminating society (Katsui, 2005, p. 70). In the West, too, "exceptional parents" often have been the driving force to overcome environmental problems of young disabled people such as the challenges of access to

education, housing needs, access to the labor market, the need for personal assistance and transport (Booth & Swann, 1987; Pascalle & Hendey, 2004).

Typically, these are parents who have higher education, prior experience of people with disabilities, and disposable economic resources (Katsui, 2005; Booth & Swann, 1987; Markova & Sultanalieva, 2013). Therefore, social stratification in the community also is reflected in the lives and opportunities of children with disabilities. This type of generalization requires further nuance to be helpful. If appearing to value or support a child with a disability is a contravention of extant cultural norms, then the best advocates for their children are those parents who have the necessary social standing to resist pressure from others in the community. This fits within Katsui's (2005) profile of the parent advocate but needs further development in this research.

State Services for Children with Disabilities

There are several legislative documents governing public service access for children with disabilities. Article 41 of the Constitution guarantees the right to education to all citizens of Tajikistan although without specifying the form. The *Law on Education* (adopted in 1993, revised in 2004) further provides for access to education for all children, including those with disabilities and special education needs, by elaborating an institutional structure of responsibilities. The *Law on Social Protection of the Disabled in the Republic of Tajikistan* (law 675, 2010) defines a "disabled person" as a person "who as a result of unfitness of health with reduction of the functions of performance of tasks of the body due to sickness, injuries, physical and mental disability which causes barriers to life activities and need to social protection."

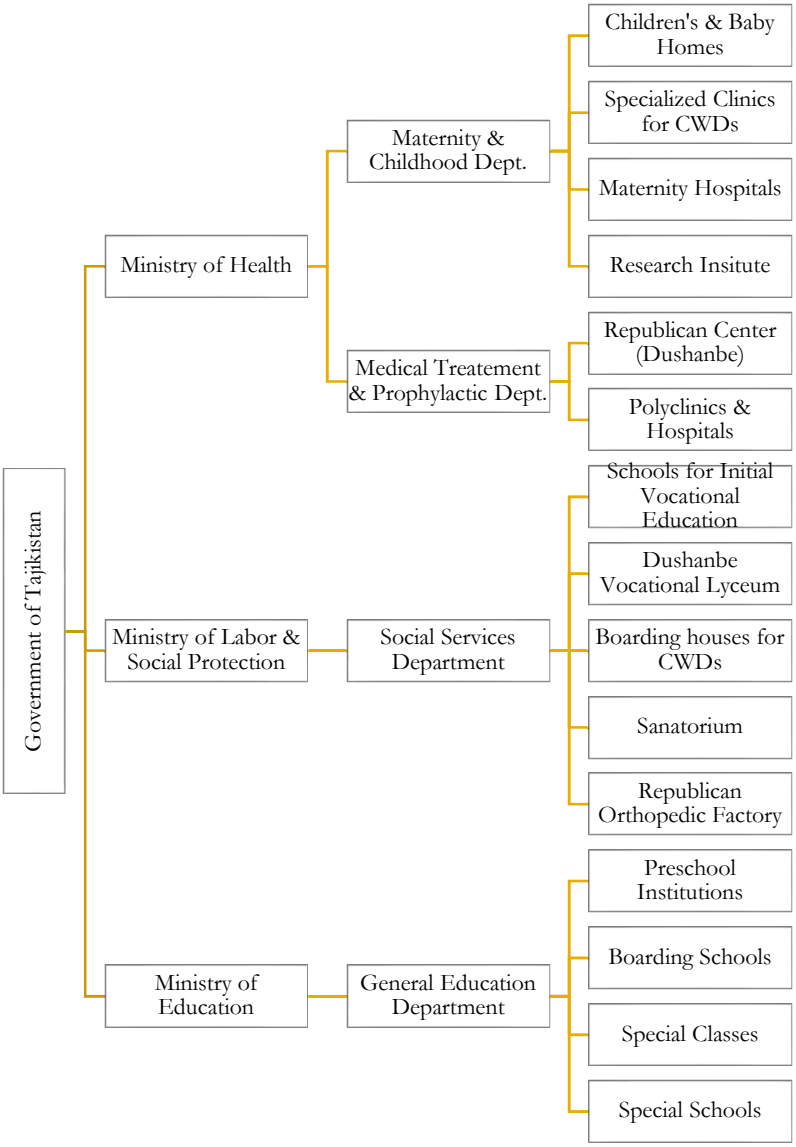
One of the main concerns of the *Law on Social Protection* is to provide for the participation of people with disabilities in the social, economic and political life of the country. Article 24 of this law guarantees people with disabilities "access and equal rights … at the level of other citizens to health,

education, recreation and tourism..." Some parents of children with disabilities have used this law in court to receive benefits for their children, but in fact there are very few state budget allocations to provide for sustainable, consistent service delivery often leaving communities to fend for themselves. At this time Tajikistan has no specific law on special or inclusive education (OECD, 2009) although the parliament is considering an Education Codex which would enshrine both inclusive education and special education provision in law (Lapham, 2018).

Furthermore, the systems of education, health and social protection operate under the auspices of three different line ministries with little coordination among them. All three of these line ministries are responsible for different types of educational institutions with both the ministries of health and labor/social protection operating residential institutions, the ministry of labor operating vocational schools, and the ministry of education operating mainstream schools and kindergartens as well as special schools, special classes within mainstream schools, and specialized boarding schools. The chart below provides a summary of this system, which the OECD (2009) describes as confusing to parents and difficult to navigate.

Figure 1.1: Distribution of responsibilities for children with disabilities in Tajikistan

Source: OECD, 2009



Tajikistan has ratified several relevant treaties and conventions to provide for more inclusive education and the protection of children's rights. This is important to note because Tajikistan's monist legal system does not differentiate between national and international law. Once ratified, both are fully binding and viewed as part of the same legal system. Ratified conventions include the Convention on the Rights of the Child (October 1993), the Convention on Economic, Social and Cultural Rights

(January 1999), the Convention on the Elimination of Discrimination against Women (September 1993), and the International Covenant on Civil and Political Rights (January 1999). Tajikistan has also adopted the 1994 Salamanca Statement on Principles, Policy and Practice in Special Needs Education and the President of Tajikistan has given the country's representative at the United Nations permission to sign the Convention on the Rights of Persons with Disabilities (February 2018). Although there are some university teachers, officials and NGOs who understand and promote the concept of inclusive education, the general public, including many educational professionals, have little or no understanding of the principles of inclusive education or how to develop it (OECD, 2009).

A working group of government agencies and civil society representatives developed a national Concept on Inclusive Education related to the National Education Development Strategy (NEDS) agreed between the Government of Tajikistan and major donors to education. Although it does not have the force of law and does not aim for the type of full education inclusion described in Article 24 of the UN Convention on the Rights of Persons with Disabilities (CRPD), it is a positive step. However, this Concept has parliamentary endorsement only through the end of 2014, and it is not clear whether or how existing legislation might be amended to institutionalize or sustain progress made within this framework. For practical purposes, this leaves children with special education needs out of policies aimed at integrating people with disabilities into society as the OECD found (2009).

Formally, mainstream schools are not designed to work inclusively to accommodate children with disabilities or other special educational needs. Furthermore, special education is the purview of a segregated system of schools and residential institutions that group children based on their disability or learning challenges. These institutions and the practice of education for children with disabilities in general are heavily influenced by a medical approach to disability and the legacy of defectology (Rouse & Lapham, 2013; Daniels, 2005; Florian & Bericevic, 2011).

Tajikistan's education system is inherited from the Soviet Union and is thus infused with the philosophy of defectology. Originally, an area of developmental psychology seeking to support children with atypical development, defectology evolved through the 20th century as a body of education practices seeking to 'rehabilitate' children with disabilities through specialized education and therapy in special schools or institutions separate from the mainstream, general education system. As the poorest republic in the Soviet Union, Tajikistan's education system inherited this way of thinking about programs for children with disabilities but did not have a strong system of special schools when the Soviet Union disintegrated. Furthermore, the social upheaval of civil war and the continuing high rates of labor migration mean that those special schools that did exist are often currently providing emergency shelter for children from very poor families or without parental care regardless of their disability status.

As a result, children with disabilities in Tajikistan have limited options for education and related support services (physical therapy, speech therapy, occupational therapy, access to assistive devices, etc.) that would normally be connected to special schools. Families can seek an institutional placement, but this will often be far from their home and conditions are very poor. Parents can try to engage teachers to come to their home on a private basis if they can afford to pay for this. Attending the local school can be very difficult or impossible, depending on the nature of the child's disability and the willingness of the school to accept the child. Often children with disabilities simply stay at home with no education at all. Thus, empowering the parents of children with disabilities to advocate for access to education requires overcoming both of these formal and informal barriers.

The Role of Parent Associations & Non-Government Organizations

This study also requires a discussion of the ways that NGOs or associations have been associated with individual empowerment, community empowerment, social capital development, and

education initiatives in the transition countries of the former Soviet Union. Since the 1990s, international organizations and development agencies have followed the disintegration of the Soviet Union into the newly independent republics, bringing with them sweeping ideas about the reform of policies and institutions in every sector of state and society. Often these ideas about post-Soviet reform were imported from the West through development assistance and technical expertise aimed at promoting democratization, strengthened market economies, and reinforcement of 'civil society' (Silova & Steiner-Khamsi, 2008).

In fact, the (re)building of the civil society became one of the central goals of post-Soviet transformations, reflecting the idea that grassroots movements embedded in NGOs and professional associations could "in turn can provide impetus for democratic reforms" (Adamson, 2002, p. 178). In the education area, this translated into the efforts to strengthen community participation in schools through boards of trustees, parent committees and school funds, which was seen as "a fundamental element of democratic civil society development" (Fomina, 2005, p. 1). The other side of civil society development in education was support for the growth of independent service providers, often built through donor-led projects that challenged the state monopoly on some aspects of education and often became semi-permanent contractors for implementation of donor-funded projects.

Regardless of international agencies and donors' intentions, efforts to build civil society by forming registered NGOs have often faced unpredictable problems and generated unintended consequences. In other words, the expected impact of community participation projects on democratization and empowerment of societies is often greater than the reality it leaves behind (Burde, 2004). There are even instances when these NGOs are currently being labeled 'foreign agents' by governments who see them as the direct result of donor projects and international development work rather than as local civil society movements.

This particular group of parent associations has an interesting history. They began as parent

support groups within largely donor-funded NGOs related to health or social protection in regional centers in various parts of Tajikistan. As the parent support groups grew and became concerned with challenges outside their immediate families and daily lives, like access to services and advocacy that required a more formal structure, some of the core groups registered formal associations. These associations have come together with other NGOs and informal parent groups to create a network of 20 organizations that have been supported by international donors, including CARITAS, the Open Society Foundations, and UNICEF. Some are specific to a city or village while others are specific to a disability (Down Syndrome, autism). The network has grown quickly and has formalized as a coalition with a charter and elections for a coordinating organization that has allowed for rotations of leadership on a regional basis. The network is hailed by each of these donors as a success because it conforms broadly to goals around civil society development, community-based service delivery, or other program-related objectives.

However, this is not the whole story. These associations also represent the legal format for collective action chosen by the mothers who founded them. They made this choice in the context of a country where international development assistance is a significant source of funding and support for people with disabilities. This has likely influenced their choice to register formal groups and to formalize their coalition. How they work within this framework, and how it influences the form and substance of their collective action is the other (more interesting) side of this story.

Chapter 2 explores the personal dimension of this journey. It includes a literature review that positions this dissertation within the existing research on empowerment, with a particular focus on parents of children with disabilities, by comparing the approaches to empowerment in the fields of community psychology and international development. The analysis of the empowerment literature and subsequent related research on the relationship between social capital and empowerment yields a theoretical framework describing empowerment as an expanding spiral of building knowledge,

confidence, and social connections.

Chapter 3 builds on this framework, providing a full description of research methods used to respond to this dissertation's central questions. It describes the qualitative methods used to build three case studies as well as the ethical considerations of conducting research with a potentially vulnerable population. This chapter also describes the systems developed for collecting, managing, and analyzing data. Finally, it provides a brief review of the literature on multiple case study methodology drawing on the work of Robert Stake. The multiple case study approach he developed allowed me to look at three distinct but related phenomena of parent-led or instigated inclusive education through the work of three different but representative types of parent groups. By studying a specific set of mothers and children in the context of their parent organization affiliation, communities and school, the multiple case study method gave me the opportunity to observe the relationships and connections essential to understanding social capital networks. At the same time, the in-depth interviews and other forms of qualitative data collection presupposed in the development of each case allows me to interrogate processes of empowerment and social capital formation in the limited amount of time available for this research. Studying these groups and the mothers who participate in them allows me to develop a more nuanced understanding about the empowerment and formation of social capital among mothers of children with disabilities in Tajikistan. I examine the following three cases:

a) *Urban Area – Specific Disability Group:* The first case is the non-governmental organization IRODA, which is located in Dushanbe (the capital of Tajikistan) and provides support for children with autism.
b) *Urban Area – No Specific Disability Group:* The second is the original Association of Parents which is based in Khujand and has been elected to coordinate the activities of other associations gathered in a coalition.

c) *Rural Area – No Specific Disability Group:* The third is a small association of parents in Bokhtar district, Khatlon oblast.

Chapter 4 builds the three case studies. By amplifying the voice of a population that is often silenced or completely invisible in Tajikistan, this research project has the potential to further empower participants by validating their experience as valuable and important. Through interviews, focus groups, and extended conversations, the mothers in each case contribute to a unique understanding of the relationships between empowerment and social capital in Tajikistan. More often viewed as the recipients of charity, public services, or knowledge from professionals and international experts, the opportunity to see themselves as expert contributors by telling their own story is quite powerful.

Chapter 5 concludes the study by examining the findings across the full sample of interviews and focus groups in response to the research questions and theoretical framework. It also provides comparison across the three cases, suggesting areas of common and divergent experiences based on the characteristics and context of each of the three associations. Finally, I suggest outstanding questions and areas for further research.

Chapter 2 : Literature Review and Theoretical Framework

Literature Review

This chapter follows the preceding introduction's overview of the study and the context of Tajikistan with an examination of the relevant literature to build a theoretical framework of empowerment. This literature review builds on and contrasts the concept of empowerment in the fields of international development and community psychology. Although the concept of 'empowerment' is used in academic literature from a wide range of fields, these two are the most relevant to the current study. Many of the theoretical underpinnings of the term originated in psychology and community psychology. However, the field of international development has taken the concept and sought to put it into practice as an explicit objective and indicator of success of projects and development assistance. Empowerment is a concept that has been used extensively in each field with both contributing to the ongoing definition and study of empowerment (Grabe, 2012).The sections that follow provide an examination of the academic and professional literature (in the case of international development) in an effort to map the development of a working definition in each field and elaborate a theoretical framework for this research.

Community psychology

To gather material for this review, I searched the table of contents and abstracts of the two key journals in community psychology from the first mention of the concept of empowerment in the major journals of the field in 1973 through the present for relevant articles and book reviews. There are 564 articles in the *American Journal of Community Psychology* (AJCP) using 'empowerment' as a key word since the journal began publishing in 1973. The *Journal of Community Psychology* (JCP) lists 389 articles beginning in 1978. Articles focusing on empowerment as a central framework are concentrated in the

mid-1990's with scholarship continuing through the present. This yielded 953 sources, which I narrowed by focusing on those with empowerment in the title or subtitle of the article, yielding 87 sources which I coded by key elements of the definition of empowerment advanced. The results are tabulated below in Table 1 and followed by further tabulation of definitional components of the elements themselves. This process allowed me to develop a composite definition of empowerment for comparison.[3]

Table 2.1: Definitional elements of empowerment in community psychology

Elements	AJCP (59 articles)	JCP (28 articles)
Learning, knowledge	19	8
Learning, gaining skills or competencies	20	7
Self-efficacy	20 (specifically) 5 (most elements)	15
Context-specific process	24	14
Connecting with others	21	12
Social capital	2 (specifically) ; 5 (most elements)	0 (specifically); 4 (most elements)
Critical awareness	8 (specifically); 9 (most elements)	6 (specifically) ; 3 (most elements)
Taking individual action	22	11
Collective action	13	2
Increase in resources	11	4
Measurement	8 individual quantitative 3 group quantitative 13 qualitative or action research studies	12 individual quantitative 0 group quantitative 5 qualitative or action research studies

[3] For a complete tabulation of each source reviewed, please refer to Appendix 3.

The definition of empowerment and its use as a theoretical framework for empirical studies in community psychology is not static throughout this time period. Angelique et al. (2013) identify two historical shifts in the ways that the field of community psychology deals with power and the linked concept of empowerment. In the late 1970s and early 1980s the field begins a slow shift from a focus on the individual to the community, including some mentions of power relations at the level of society as a whole. Most definitions of empowerment prior to 2010 focused on gaining access, mastery, and control over self, group, and others (Brodsky & Cattaneo, 2013). Measurement during this period remains mostly at the level of the individual using quantitative models borrowed from other disciplines within psychology. In the mid-2000s there is a second shift toward greater political awareness, creating "a more nuanced conceptual framework of social power that incorporates psychological and political dimensions" (Angelique et al. 2013, p. 730). Still, the use of quantitative models for measuring empowerment in and among groups remains rare and evenly dispersed over time. Qualitative studies or action research are much more likely to be employed for empirical work with groups using empowerment in this field.

Within these shifts, there are some definitional elements that remain constant and others that evolve significantly or come into the field at a later date. Much of this evolution can be traced through the work of Julian Rappaport, himself indebted to the Cornell Empowerment Group (1987) for his theoretical start, and Marc Zimmerman. These two scholars have done a great deal of the theoretical work on empowerment in the field of community psychology. They are either referenced or critiqued by the rest of the field, beginning with the definition:

> Empowerment … both individual determination over one's own life and democratic participation in the life of one's community, often through mediating structures such as schools, neighborhoods, churches, and other voluntary organizations. Empowerment conveys both a psychological sense of personal control or influence and a concern with actual social influence, political power, and legal rights. It is a multilevel construct applicable to individual

> citizens as well as to organizations and neighborhoods; it suggests the study of people in context. (Rappaport 1987, p. 121)

There are several good reviews of the scholarship in Community Psychology that develop nuances in the theory of empowerment.[4] In the paragraphs that follow, I discuss four threads of the definition of empowerment within the field community psychology that emerges from my reading of this scholarship. The grouping is my own, chosen for clarity of further discussion of the theoretical model for this research. In broad strokes, these are 1) self-efficacy; 2) the importance of context; 3) connections between individuals and groups; and 4) critical awareness.

1) Knowledge, skills, and self-efficacy

The field of community psychology frames the discussion of learning, gaining knowledge, and developing skills in terms of and in relation to the psychological concept of self-efficacy. In Rappaport's definition (1987, p. 121), this is characterized as "a psychological sense of personal control or influence." Bandura (1977, p. 193) developed this framework in the field of psychology and defines self-efficacy as "the conviction that one can successfully execute the behavior required to produce [specific, desirable] outcomes." This is an important departure from the model of outcome expectations previously favored in the field of psychology because it makes the link between knowing how something should work (a+b=c) and the confidence to achieve the outcome (c) when acting on the knowledge of how to do it (a+b). A person must believe in their ability to achieve the desired outcome in order to be sufficiently motivated to try:

> The strength of people's convictions in their own effectiveness is likely to affect whether they will even try to cope with given situations… Not only can perceived self-efficacy have directive influence on choice of activities and settings, but, through expectations of eventual success, it can affect coping efforts once they are initiated. Efficacy expectations determine how much effort people will expend and how long they will persist in the face of obstacles and aversive

[4] See Zimmerman, 2000.

> experiences. The stronger the perceived self-efficacy, the more active the efforts… Expectation alone will not produce desired performance if the component capabilities are lacking. Moreover, there are many things that people can do with certainty of success that they do not perform because they have no incentives to do so. Given appropriate skills and adequate incentives, however, efficacy expectations are a major determinant of people's choice of activities, how much effort they will expend, and of how long they will sustain effort in dealing with stressful situations. (Bandura, 1977, pp. 193-4)

Thus, self-efficacy combines the acquisition of information, knowledge, and skills with the confidence to apply them successfully. This thread of the definition of empowerment implies learning in a supported environment where individuals can gain fluency of knowledge and practice with recourse to support until they feel confident enough to act independently. In addition, organizing or engaging in collective action can generate or enhance feelings of self-efficacy (Florin & Wandersman, 1990; Christens, 2010).

2) Importance of context. In his outline for a theory of empowerment, Rappaport (1987, p. 139) notes that "the historical context in which a person, program, or policy operates has an important influence on the outcomes of the program." Zimmerman (1992) also notes the importance of context for developing any measurement of empowerment. This view is reflected to some degree in all of the articles reviewed and stated outright in nearly half of the pool. This acknowledgement of context's importance may seem self-evident, but in fact, it is an important addition from community psychology because it departs from psychology's near-exclusive focus on the individual alone. It has supported the expansion of the literature on empowerment from individuals to groups and organizations, leading to the development of concepts of empowering and empowered organizations (Maton & Salem, 1995; Maton, 2008).

Beyond looking at the close and individual context of organizations, families, and other circles of acquaintance, the exploration of context in empowerment theory opens the door for examination

of the broader social context and its embedded power relationships. Serrano-Garcia (1994, p. 433) pushes this forward without direct references to power by advocating for a "focus on diversity [that] challenges us to think more about the empowerment of groups as well as to embed our understanding of individual empowerment in cultural contexts." Other scholars use the foundation of context to build the thread of critical awareness in empowerment theory.

3) Connecting with others

Similar to the discussion of context, community psychology emphasizes that people do not exist in a vacuum. Their connections or lack thereof to others are vitally important and play a role in the process of empowerment. Schutt and Rogers (2009) specifically note the importance of finding others who share the same or similar problems, a finding reflected in my own research. Indeed, scholars who have criticized the study of empowerment in community psychology have found the concept too individualistic and focused on a zero-sum conception of power that ignores the possibility of community and collaborative relationships (Riger, 1993). This is an important criticism to keep in mind as the discussion of empowerment shifts to other fields, in particular those focused on allocation of material resources, like economics and international development.

However, within the field of community psychology, the positions by Riger, Rappaport, and Zimmerman converge in many ways (Speer, 2000). In particular, the interactional dimension of empowerment that Zimmerman (1995, 2000) describes has parallels with Riger's advancement of the communal or collective quality to empowerment (Speer 2000, p. 53). Rappaport (1987, p. 121) explicitly references "mediating structures such as schools, neighborhoods, churches, and other voluntary organizations" as well as "social influence, political power, and legal rights." Chavis and Wandersman (1990) also see a reciprocal relationship between a sense of community and a sense of personal power to influence events through participation within that community. Qualitative studies

and observations about the nature and importance of interactions between individuals, within groups, and between groups are important for the field of community psychology as it seeks to address the field of psychology, which is more individually focused with an emphasis on quantitative measurements.

There is a great deal of depth to this exploration that touches on concepts of citizenship, collective action, and civil society. "The transformative power that empowerment theory seeks to promote is developed and exercised in and through relationships, as well as emotional, cognitive and behavioral processes" (Christens, 2012, p. 117), therefore empowerment needs a theoretical description of non-monetary sources of power and influence in addition to a simple understanding of economic resources. However, one of the difficulties of empowerment theory in this field is that the connection to other theoretical frameworks looking specifically at the connections between individuals is disparate and loose. In the last few years, scholars have paid greater attention to this weakness, particularly as empowerment has trickled into other fields with the attendant risk of becoming too conceptually diffuse. Some in the field of community psychology have turned to social capital to fill this gap (Christens 2012), which is explored in greater detail later in this chapter.

4) Critical awareness, action, and empowering others

Building on the work of Paolo Freire (1973, 2000) and liberation psychology (Martín-Baró et al., 1996), the field of community psychology began incorporating critical awareness into concepts of empowerment in the early 2000s. While earlier theories of empowerment have explained the importance of gaining control over one's personal life and community participation (see Rappaport 1981, 1987), the field as a whole did not focus on the analysis of power dynamics needed to unveil social marginalization and structural discrimination or to develop research that considers well-being, and social justice (Angelique et al., 2013). This began to change as scholars working in the field of

community psychology rediscovered and increasingly returned to the 'power' inherent in 'empowerment' while also following threads of scholarship emphasizing the connections between and among individuals (see Angelique et al., 2002; Davidson et al., 2006; Nelson, Prilleltensky, & MacGillivary, 2001; Prilleltensky, 2008.)

In this thread of scholarship, critical awareness can be defined as an understanding among individuals of the connections between broader social, political and economic context and the opportunities and options available in their own lives. Balcazar et al. (2012, p. 283) posit that "individuals who participate in this process [of developing critical awareness] can build capacities and skills while joining with others to take action against their oppressive structural context. Participation can lead to gradual change over time and individuals can become critical thinkers and proactive." This is the difference between understanding individual discrimination and structural discrimination. Angelique et al. (2013) rightly critique explorations of empowerment that shy away from critical theory and direct engagement with structural power. Although the field of community psychology has tacitly addressed issues of power and social change in earlier scholarship, including to some extent Rappaport's original definition, she argues that those working in the field must lay the "groundwork from which to move beyond notions of empowerment toward a more explicit attention to societal power imbalances" (p. 728). Agreeing with this analysis, I include critical awareness as an integral element of empowerment in the theoretical model that follows.

Community psychology has sought to operationalize critical awareness by developing frameworks such as 'empowering community settings' (Maton, 2008; Paloma et al., 2010) and 'empowering community narratives' (McDonald et al., 2007; Rappaport, 2000). Critical awareness remains a theme of exploration and research in this field with evolving attention to the role of research. Cattaneo et al. (2014, p. 433) rightly caution that "to avoid the danger of not questioning, or worse,

strengthening the status quo in the name of empowerment, empowerment needs to be firmly relocated on the bridge between individual and social power and anchored in the priorities of marginalized communities."

In addition to developing a working definition of empowerment, I also scanned literature related to the field of community psychology with a particular focus on those fields like social work that seek to operationalize the term. Originating in community psychology and social work, empowerment as a theoretical construct grew out of advocacy for a departure from the professional/client model toward more collaborative service provision in North America during the 1990's (Christens, 2012). This new approach required a shift in the field such that "empowered" families, regardless of the challenges they face, are considered an important resource (Stroul et al., 1996). The level of collaboration with them can determine the success or failure of professional services (DeChillo, Koren, & Schultze, 1994). This has not always been the case. In fact, families have faced stigma as the potential cause of their children's problems through neglect or bad parenting (Friesen & Stephens, 1998, p. 232) which has sometimes led to parents banding together to provide services for their children and then offering services on a professional basis.

For example, McCammon, Spencer, and Friesen (2001) write persuasively about the multiple roles that parents of children with serious emotional problems can play, including their potential to educate and train professionals, students, and other family members. Citing examples in Illinois, Pennsylvania, Maryland, and Rhode Island, Ignelzi & Dague (1995) make the case that family members of children with emotional and behavioral challenges have long been providing services to their own and other families that include self-help groups for emotional support and information exchange as well as actually delivering or coordinating service provision. They further characterize the 'next step' in parent involvement as providing direct services for fees, including as mentors, case managers, early

intervention workers, advocates, in-home support staff, respite providers, service planners, and managers of family cash grants (McCammon, Spencer, & Friesen, 2001). This history has particular relevance for a study of mothers of children with disabilities and has great resonance with the reported development trajectory of the parent associations participating in this study (Lapham, 2013).

Empowerment and international development

International development is a broad field with contributions from disciplines that include economics, political science, and sociology as well as fields including women's studies, international affairs, and community psychology. As a field, it is deeply motivated by the operationalization of theoretical frameworks but sometimes without the discipline that fealty to a specific discipline would impose. Empowerment has been widely operationalized through the field of international development in a variety of ways that affect funding and other support to organizations like the parent associations participating in this research, creating part of the context in which they operate. The field of international development also may be partially responsible for the lack of precision and wide-ranging use of the term that others have criticized (Alsop, Bertelsen & Holland 2006; Zimmerman 2000).

Indeed, a simple Google search for the term yielded 81.8 million results with the World Bank ranking at the top of the list just after its Wikipedia entry. Since operationalization is inextricably connected to the ability to act in the field by designing, funding, and implementing projects to test or expand theory, I worked with the assumption that those organizations with the largest resources and/or the greatest amount of work associated with an empowerment framework would have the largest role in defining the way that framework would be understood in the field. Since so much of the documentation of empowerment frameworks in international development has emerged from the Bank's projects, including the two books framing the concept reviewed here, I have focused my review

on the way that the World Bank has used empowerment as a theoretical framework to underpin international development assistance or projects. It is also worth noting that since 1996, the World Bank has provided 85 lending and grant-funded projects totaling approximately $843 million in Tajikistan (The World Bank, 2013).

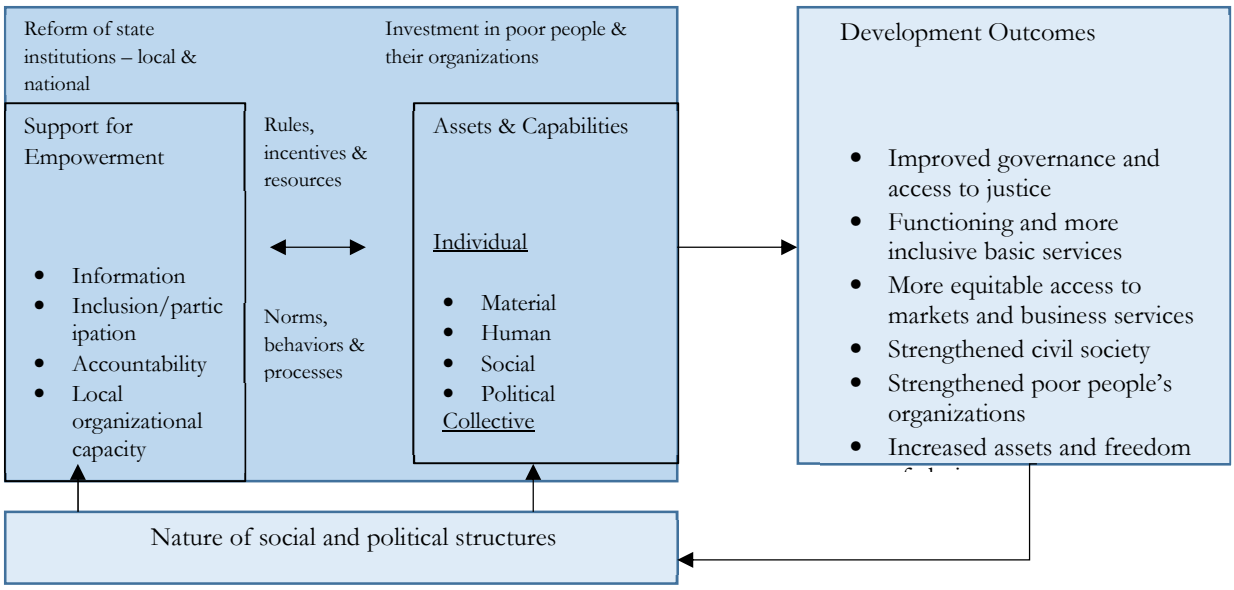
The World Bank began exploring empowerment as a concept in the *World Development Report 2000/2001: Attacking Poverty*. This was closely followed by the publication of *Empowerment and Poverty Reduction: A Sourcebook*[5] in 2002 edited by Deepa Narayan-Parker, at the time a Senior Advisor for Poverty Reduction and Economic Management. The book defines empowerment and provides some meta-analysis of the Bank's work, which are further explored with short cases from projects around the world to elaborate specific lessons or examples that support the definitional elements in some way. This volume aims to define empowerment to others at the Bank with an interest in participatory development and, perhaps, to convince those less willing to adopt the approach of its instrumental value to help Bank projects meet their goals. The executive summary works hard to make this case:

> A growing body of evidence points to the linkages between empowerment and development effectiveness both at the society-wide level and at the grassroots level. Empowerment approaches can strengthen good governance, which in turn enhances growth prospects. When citizens are engaged, exercise their voice, and demand accountability, government performance improves and corruption is harder to sustain. Citizen participation can also build consensus in support of difficult reforms needed to create a positive investment climate and induce growth. (p. xvii)

Narayan-Parker (2002, pp. 13-30) goes on to define four elements of empowerment that interact with each other to produce desired development outcomes: access to information, inclusion and participation, accountability, and local organizational capacity in the framework presented in Figure 2.1.

[5] Cited by 715 on Google Scholar

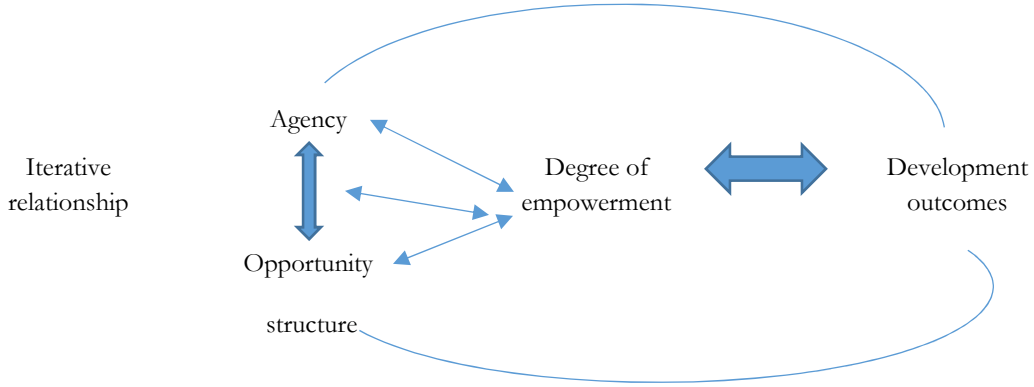
Figure 2.1: Empowerment Framework
Source: Narayan-Parker, 2002, p. 23



Alsop and Heinsohn (2005) extended the empowerment framework used by the World Bank, which is further continued in the World Bank's publication of *Empowerment in Practice: From Analysis to Implementation* (Alsop, Bertelsen, & Holland 2006).[6] This book is dedicated to further elaborating empowerment as a framework for international development projects and providing case studies that illustrate the use of the empowerment framework used in Bank projects in different sectors. The authors note the differing definitions of empowerment as the term is used more widely in the field. They attribute the theoretical underpinnings to literature on democratization and decentralization, human rights, and poverty reduction theories beyond traditional economics with particular attention to Sen's capability theory (Alsop, Bertelsen, & Holland 2006, p. 2).

[6] Cited by 334 on Google Scholar

Figure 2.2: The relationship between outcomes and correlates of empowerment
Source: Alsop, Bertelsen, & Holland 2006, p.10



This model solidifies the definition Narayan-Parker (2002) has laid out and provides a better idea of the ways that the elements of her definition relate to each other. Empowerment in this framework has come to be defined as the capacity to make effective choices "that is, to translate their choices into desired actions and outcomes" (Alsop & Heinsohn, 2005; Alsop, Bertelsen & Holland, 2006, p. 1). The dynamic within this framework is between agency and opportunity structure. Agency is the capacity to make choices and attempt action; it is "largely predicted by their asset endowment [or the] resources that equip actors to use economic, social and political opportunities, to be productive, and to protect themselves from shocks" (Alsop, Bertelsen, & Holland, 2006, p. 11). Opportunity structures are defined as the "aspects of the institutional context within which actors operate that influence their ability to transform agency into action" (Alsop, Bertelsen, & Holland, 2006, p. 10, p. 13). They can be formal (i.e. legal frameworks) or informal (i.e. social norms).

Thus, in applying an empowerment framework, the authors seek ways to change asset endowments of individuals and groups and to modify opportunity structures, in particular through interventions supported by the Bank (Alsop, Bertelsen, & Holland, 2006, p. 29). Acknowledging roots in the capability approach, empowerment's interaction of agency and opportunity structure is "based

on tackling difference in capabilities that deny actors the capacity to make transforming choices" (Alsop, Bertelsen & Holland, 2006, p. 15). The paragraphs that follow identify the key terms of the definition of empowerment – asset endowment and opportunity structure – and briefly discusses approaches to operationalization and measurement.

1) Asset endowments

Asset endowments can be tangible resources, such as land, equipment, cash or access to credit, etc. However, there are also more abstract, intangible components of asset endowment. Knowledge, and specifically education and the related increases in human capital are important assets. Information is also an asset with a direct relationship to opportunity structures. Access to information here is conceptualized as a two-way flow between governments and citizens, wherein citizens know enough about their entitlement to existing services to make use of them and governments know how services are used. There is also an economic function for information in terms of transparent prices and financial services. "Without information that is relevant, timely, and presented in forms that can be understood, it is impossible for poor people to take effective action" (Narayan-Parker, 2002, p. 19). The focus on accessing information without necessarily developing the skills and competencies to use it that are contained in community psychology's emphasis on self-efficacy is an important difference in the way that the two fields treat this component of empowerment.

Connection with others, in particular in the form of social capital, is seen as an important part of the asset endowment for individuals and communities. However, this asset has a complex relationship to opportunity structures and is not seen as an unalloyed good.

> From the networks perspective, the clear challenge to social capital theory, research, and policy is ... to identify the conditions under which the many positive aspects of bonding social capital in poor communities can be harnessed and its integrity retained (and, if necessary, its negative

> aspects dissipated) while simultaneously helping the poor gain access to formal institutions and a more diverse stock of bridging social capital. (Woolcock & Narayan-Parker, 2006, p. 40)

For example, Sen (2004) notes from the vantage point of an economist the possibility of strong connections within a group excluding those who are not members. In this sense, social capital is not "a general purpose asset" like other forms of capital (p. 41) and may detract from the asset endowment of a community rather than enriching it.

2) Opportunity structure

Of the two components, opportunity structure is more complex, including the related ideas of participation, choice, accountability, and organizational capacity. Narayan-Parker's (2002) treatment of empowerment focuses on formal institutions, in particular the market and governance, which can be shifted by investment in poor people and 'their organizations' and reform of formal institutions. Inclusion and participation are described as the 'who' and 'how' of development processes whereby "an empowering approach to participation views poor people as co-producers with authority and control over decisions and resources – particularly financial resources – devolved to the lowest appropriate level" (Narayan-Parker, 2002, p. 19).

Narayan-Parker (2002) is clear that inclusion of the poor and "other traditionally excluded groups" is important and that participation must be in some way binding so that it does not become "another cost imposed on poor people without any returns" (p. 20) and discusses the importance of legal frameworks that require the inclusion of traditionally excluded groups (Narayan-Parker, 2002, p. 42). She further defines five types of participation, which include direct participation, representational participation through membership-based organizations, political participation through elected representatives, information-based participation where data is aggregated and reported to those who make decisions, and participation through competitive market mechanisms.

No preference for the form of participation is expressed. However, participation through consultation followed by transparent dissemination of decisions is characterized as most appropriate for "sector-wide or economy-wide" policymaking (Narayan-Parker, 2002, p. 24). Much of the discussion of participation refers to the poor as "beneficiaries" (Narayan-Parker, 2002, p. 35) and focuses on ways that those presently excluded could participate through slight modifications to existing systems or simply by participating in research that informs better policy decisions and is thus worth the initial cost to Bank interventions (Narayan-Parker, 2002, p. 43). This analysis begs the question of how much empowerment is actually taking place and the extent to which including specific constituencies in planning development projects is empowering.

Accountability, another element of opportunity structure, is "the ability to call public officials, private employers, or service providers to account, requiring that they be answerable for their policies, actions, and use of funds" (Narayan-Parker, 2002, p. 20). Three forms of accountability are discussed: political accountability through the ballot box, administrative accountability through the rules and regulations governing public agencies, and social or public accountability which reinforces the first two by holding "government agencies accountable to citizens" (Narayan-Parker, 2002, p. 21) with government in turn responsible for designing these mechanisms (Narayan-Parker, 2002, p. 42). Access to information is a necessary component for accountability. In order "for citizen feedback to affect decision making, information has to be in the public domain; it has to be collected quickly on a key set of core performance indicators…; and it has to be available to decision makers who have to be held accountable to respond to feedback" with disbursement of Bank funds linked to the outcomes (Narayan-Parker, 2002, p. 48). This remains consistent in the volume by Alsop, Bertelsen, and Holland (2006).

Consistent with the definition of agency, choice is an important conceptual thread in the Bank's work. Choice within a transparent market framework, for example of providers of technical assistance, is presented as an example of the links between accountability and participation, in some sections going so far as to equate choice with participation (Alsop, Bertelsen, & Holland, 2006, p. 31). Decentralization supports participation and empowerment as well by "moving decision making closer to people [which] will lead to better public decisions that reflect local priorities" (Narayan-Parker 2002, p. 25). More equitable decision making benefitting poor communities is not necessarily a given, as the highly decentralized system of school financing in the United States demonstrates.

The last component of empowerment that Narayan-Parker (2002, p. 26) lays out is a hybrid of asset endowment and opportunity structure, local organizational capacity in both formal and informal organizations that "include or represent poor people's interests." She incorporates some of the aspects of connection with others and the capacity for collective action present in the definition of empowerment that emerges from the field of community psychology, including a reference to social capital:

> Organized communities are more likely to have their voices heard and their demands met than communities with little organization. Poor people's membership-based organizations may be highly effective in meeting survival needs, but they are constrained by limited resources and technical knowledge. In addition, they often lack bridging and linking social capital, that is, they may not be connected to other groups unlike themselves or to the resources of civil society or the state. It is only when groups connect to each other across communities and form networks or associations – eventually becoming large federations with a regional or national presence – that they begin to influence government decision making and gain collective bargaining power with suppliers of raw materials, buyers, employers, and financiers. (p. 22)

There is a simultaneous skepticism of both government and social movements that balances uncomfortably within the Bank's treatment of local organizational capacity in both volumes Narayan-Parker, 2002; Alsop, Bertelsen, & Holland, 2006). As a result, the development of formal organizations

is treated simultaneously with the development of connections among people needed to start and sustain them, skating over the formation of social capital in the context of inequality or conflict, in particular (Narayan-Parker, 2002, pp. 25, 223). Issues of power and conflict are discussed in three paragraphs, recognizing that "powerful social groups control entry and exit options of those excluded from full participation in social, economic, and political life at the community and national levels" (Narayan-Parker, 2002, p. 25). Capacity development is also described in ways that either conflate or privilege economic participation over political participation, for example through discussions of vouchers and school choice as empowering of the poor (Narayan-Parker, 2002, p. 36). In the same discussion, there is reference to capacity among local organizations to enter contracting relationships with governments for service delivery. The application of these principles reflect ambivalence with a focus on very small, local initiatives and the legal framework of the macro-economy (Narayan-Parker, 2002, p. 57) without examination of the linkages and potential structural barriers between the two.

3) Measurement

Alsop, Bertelsen, & Holland (2006) provide some guidance on measuring changes in empowerment, which is essential to any operationalization of the framework through international development projects. Unsurprisingly, the goal of measurement is to capture the relationship between increases in empowerment and the achievement of desired development outcomes. They suggest three basic groups of indicators:

1. Choice: is it possible to make a choice?
2. Use: does the individual or group make a choice?
3. Achievement: does the choice result in the desired outcome? (Alsop, Bertelsen, & Holland, 2006, p. 17).

In dealing with the complexity of empowerment (p. 37) and in hopes of identifying entry points for intervention, they further separate measurement into domains, which include the state, the market and society, and macro-, intermediary, and local levels. Degrees of empowerment may or may not correlate across domains and levels (Alsop, Bertelsen, & Holland, 2006, p. 20). It is clear that the authors have a steep hill to climb with their audience at the World Bank in discussing measurement. They tackle head on the question of quantitative vs. qualitative measurement, making a case for mixed methods. In some instances, their advocacy sounds half-hearted, focusing on the best they could expect in the context of strong preferences among many at the Bank for quantitative measurements and complex statistical models by showing ways that qualitative data can be quantified (p. 38).

In other instances, they make a case for measuring empowerment through indirect indicators related to asset endowment and opportunity structure with a particular focus on indicators that can be measured through existing research efforts. For example, in measuring asset endowment Alsop, Bertelsen & Holland (2006, p. 33) recommend using data from the Integrated Questionnaire for the Measurement of Social Capital (IQMSC), the Living Standards Measurement Study (LSMS), and the Household Budget Survey. Using the example of social capital, literature associated with the Bank gives an idea how this might framed:

> The synergy view stresses that inclusive development takes place when representatives of the state, the corporate sector, and civil society establish common fora through which they can identify and pursue common goals. Social capital is treated as a mediating variable; it is shaped by public and private institutions, and yet has important impacts on development outcomes. (Woolcock & Narayan-Parker-Parker, 2006, p. 46)

Reflections: Comparing the two approaches

Researchers in the field of international development could have drawn on empowerment theory elaborated previously in psychology and community psychology, but have conspicuously chosen not to do so, as demonstrated by the lack of any citations of Perkins, Riger, Rappaport, Wandersman, or Zimmerman or other foundational researchers from the field of Community Psychology in their early writing on empowerment (Narayan-Parker, 2002; Alsop, Bertelsen, & Holland, 2006). The terminology in the models developed for the World Bank (Narayan-Parker, 2002; Alsop and Heinsohn, 2005; Alsop, Bertelsen, & Holland, 2006) echoes the discussion of empowerment in Community Psychology, albeit with some important differences. Both emphasize the importance of context as the stage for empowerment as a process, although the approach here is much more focused on macro- or group characteristics such as gender, religious affiliation, and income level that might easily be identified in a large development project and economic participation. Narayan-Parker tells us that "a society's formal and informal institutions are a reflection of its history, culture, politics, and geography. Approaches to empowering poor people to participate in governance and market activity and invest in their own assets are necessarily context specific" (Narayan-Parker, 2002, p. 75). This is where the similarities end despite the overlap in terms indicated in Table 2.

Table 2.2: Definitional elements of empowerment

Elements	Community psychology	International development
Learning, gaining skills or competencies	Inextricably related to self-efficacy	Access to information; skills for labor market or community participation
Self-efficacy	The confidence to use new skills or knowledge believing that your actions can make a difference	Not present.

Context-specific process	Empowerment takes place within a framework of culture, norms and relationships. Some in both fields reference social capital.	
Critical awareness	Understanding oppression as an interaction with political context and structural discrimination	Not present – emphasis on the right of the individual to participate in the status quo.
Taking action	End result of empowerment	Instrumental result of empowerment
Increase in resources	Enabling factor	End result
Measurement	Individual level with validated instruments; more qualitative studies at community level	Quantitative measures at all levels; Data from household surveys not validated to the concept of empowerment

The definitional differences or variations in the importance assigned to each element across the two fields can be grouped broadly into three categories: 1) the treatment of learning both skills and knowledge in relation to each other and the concept of self-efficacy; 2) the relationship between taking action and critical awareness; and 3) the relationship between the outcomes and measurement of empowerment.

1) Learning and self-efficacy

The field of community psychology frames the discussion of learning knowledge and skills in terms of self-efficacy. In the empowerment model in community psychology, self-efficacy's combination of knowledge / skills and confidence is integral and inextricable. This is a significant difference from the way that knowledge and skills acquisition is treated in the empowerment literature in international development where the knowledge or skill itself is the more important component despite passing references to 'psychological assets' as part of an individual's asset endowment (Alsop, Bertelsen, & Holland, 2006, p. 11). There is also a consideration of transparency through accessible information

that is integral to accountability of governments before citizens and service providers before beneficiaries but without the gains in confidence and capacity for individual action inherent in self-efficacy. In some ways, this relationship reflects the professional / client approach that inspired Rappaport and Zimmerman to use empowerment as a theoretical framework in the first place.

2) Critical awareness and collective action

In the empowerment framework advanced by Narayan-Parker (2002) and Alsop, Bertelsen, & Holland (2006) for the World Bank, there is little reference to time or process in generating these connections or the capacity to work collectively. There is also a much greater focus, as would be expected from the World Bank, on participation in the economy and operationalization of the empowerment framework for large and medium-scale interventions. Most importantly, in this presentation of empowerment, there is no discussion of critical awareness or structural discrimination beyond cultural institutions visible at the community level, such as the exclusion of women from village councils. Empowerment thus becomes the right to participate in the status quo on an equal basis with other individuals, even in ways that could subvert the social structures that might bring about deeper change.[7] Although Narayan-Parker (2002, p. 21) asserts that "when poor people can hold [service] providers accountable, control and power shifts to them," she does not address the potential for inequality or structural discrimination inherent in setting up the framework within which "the poor" can hold others accountable. Advocacy to make the existing system work as intended in regulatory frameworks is reflected in my research in Tajikistan and is a step in the process of empowerment. It is not by any means the final destination.

[7] See the example of Parent Teacher Associations in Colombia (Narayan 2002, p. 36)

There is also a strand of reasoning in this work that casts empowerment and participation as devolving or decentralizing responsibility for services. Development projects should make progress "establishing partnerships with poor people in the co-production of local public goods, particularly basic education;" however, there is need for additional investment in "information disclosure, social accountability, and local organizational capacity [in order to] overcome the risk of capture by local elites and [to achieve] long-term sustainability" (Narayan-Parker, 2006, p. 75). Knowing her audience, Narayan-Parker builds on a lack of trust in governments to deliver public goods in an attempt to advocate for more equitable participation of marginalized groups.

The field of community psychology began incorporating critical awareness in the 1990s. The operational definition in the field builds on Paolo Freire's (1973) work as well as liberation psychology (Martin-Baro, 1994), to define critical awareness as an understanding among individuals of the connections between the social, political and economic context and the power and opportunity structures of their own lives, into concepts of empowerment. Community psychology has sought to operationalize critical awareness by developing frameworks such as 'empowering community settings' (Maton, 2008; Paloma et al., 2010) and 'empowering community narratives' (McDonald et al., 2007; Rappaport, 2000). There is very little of this concept reflected in the empowerment framework developed by the World Bank where there is a much greater focus on economic participation both in terms of providing services or labor and in terms of acting as informed consumers of goods and services.

In community psychology, there is also a critique of empowerment as a zero-sum game that shifts power from one group to another, ignoring or at the expense of more collective social structures (Riger, 1993). Alsop, Bertelsen, & Holland (2006, p. 2) pay this concern a passing mention but do not attempt to address it throughout the chapters that follow. Given the acknowledged roots of their

empowerment framework in the capability approach, this is a missed opportunity. The explicit understanding of capability in relation to power and social structures (i.e. opportunity structures) through critical awareness should serve to differentiate empowerment theory in international development from the capability approach (Alsop, Bertelsen, & Holland, 2006, p. 23). Instead, the authors hint at the possibility without making a commitment, contributing to the general and sometimes amorphous nature of the framework. In the end, it is also development agencies rather than individuals or communities who decide whether empowerment should be pursued as a goal at all or is so incidental to core project goals as not to be worth the effort (Alsop, Bertelsen, & Holland 2006, p. 59). However, there is passing acknowledgement that participation is viewed as instrumental, so-called attempts to empower might lead to the co-opting of civil society that might desire deeper change (Narayan-Parker, 2002, pp. 35, 46).

3) the relationship between the outcomes and measurement of empowerment.

Each field look at empowerment both as an intrinsic and an instrumental good, with slightly more focus on the instrumental value of empowerment in the World Bank, likely ascribable to the goal of creating an operational framework to structure interventions. Community psychology focuses on taking action, either individually or collectively as a result of empowerment (Hooghe, 2003; Kieffer, 1984; Perkins et al., 2002; Putnam et al., 2004; Sirianni & Friedland, 2001; Wandersman & Florin, 2000; Wolff, 1987 & 2001) although significantly more studies in the field have focused on individual rather than group empowerment (Maton, 2008). Perhaps as a result of this individual focus, much of the work on evaluating empowerment in this field focuses on validated instruments for use with individuals.

It is also important to measure empowerment as a continuum that may not be linear in terms of relationships between elements or direction. This view is prevalent in community psychology, and

both Narayan-Parker (2002) and Alsop et al. (2006) take pains to recognize this. However, misconceptions and misuse of empowerment certainly exist in the field of international development. For example, Brodsky and Cattaneo (2013) question the appropriateness of empowerment as a goal for some development projects:

> The unremitting and extreme power inequalities facing Afghan women put them at a profound risk, and we argued that empowerment as a goal would have been immediately unrealistic, potentially disillusioning, and even dangerous. (Brodsky and Cattaneo, 2013, p. 336)

Whether this is true depends on the expectations, goals, and indicators of success set within development projects account for context in design, implementation, and evaluation. Changing power dynamics or social position takes place even for members of groups facing high degrees of discrimination and indicate that it is possible to speak about empowerment even for groups at risk. Empowerment must involve external relationships and discussions of power or at least the relationship of one person to another. Unfortunately, Brodsky and Cattaneo stay only at the micro-level rather than incorporating the structural component of critical awareness. They (2013, p. 346) focus at the individual level to contrast resilience and empowerment, using the story of a young Afghan woman who escapes a forced marriage as an example of resilience because it is not possible for her to change the structural dynamics of power on her own or even in concert with those who have taken her in to protect her.

I agree with the authors' assessment of resilience, but argue in the theoretical model below that this could be important as a first step but, on its own would be insufficient to empowerment. This example is also resonant with the cases in Tajikistan where association members are trying to change others' behavior in relation to themselves and their children at both the micro- and macro-levels. However, drawing the connection between resilience and self-efficacy on one hand and individual and group connections on the other is essential to understanding empowerment. Several

researchers in both fields have drawn the same conclusion in different ways (Christens, 2012; Gibson & Woolcock, 2008; Maton, 2008).

Social Capital and Empowerment

Social capital is used to illustrate the importance of individual and group connections in both the fields of community psychology (Christens, 2012; Grabe, 2012) and international development (Alsop, Bertelsen, & Holland, 2006, p. 9) in discussions of empowerment. There has also been a significant parallel development of social capital theory on its own within the field of international development, drawing on economics and political science. It is an attractive concept because it has the potential to fill explanatory gaps in empowerment theory related to the connections between and among individuals and groups. As a result of these considerations, social capital merits a discussion on its own terms to pull together some of the loose threads of the preceding text, beginning with an exploration of the roots and definitions of social capital theory.

Putnam (2001) asserts that the term 'social capital' has been coined at least six times during the twentieth century, while Schuller (2000) has suggested that its roots lie in a variety of intellectual traditions, including Alexis de Tocqueville's writing on voluntary associations, Elizabeth Bott's work on social networks, John Dewey's ideas about shared concerns, Jurgen Habermas' discussion of trust, Amitai Etzioni's writing on communitarianism, and Albert Bandura's research on self-efficacy. There are also examples of scholarship specific to the field of disability studies that explore the links between inclusion and social capital (Bates & Davis, 2004). However, there are three contemporary scholars whose theoretical work on social capital has formed the foundation of the current literature: Pierre Bourdieu, Robert Putnam, and James Coleman.

Pierre Bourdieu began the contemporary discussion of social capital, which he defined as "the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition" (Bourdieu, 1985, p. 248). These ideas were first published in French and have only subsequently been included in the academic literature – a phenomenon that Portes (2000a, p. 3) rightly characterizes as lamentable because of the strength of the analysis. Bourdieu further tells us that "the profits which accrue from membership in a group are the basis of the solidarity which makes them possible" (Bourdieu, 1985, p. 249). In considering the social capital developed among mothers of children with disabilities in Tajikistan, it is important to keep in mind the stigma, isolation, and exclusion which make forming new groups and relationships particularly important.

The development of social capital in the English-language academic literature has been led by Robert Putnam, a political scientist, and James Coleman, a sociologist. Their working definitions are similar. Putnam defines social capital as the trust, norms and networks that can improve the efficiency of society by facilitating coordinated actions (Putnam, 1993, p. 167). James Coleman defines social capital as a resource available to individual actors through social structures that "is productive, making possible the achievement of certain ends that in its absence would not be possible" (Coleman, 1988, p. S98). Coleman's choice to apply the concept to the sociology of education, in particular, the role that social capital plays in facilitating the development of human capital, is fortuitous for the purposes of this research because it addresses inequalities through interaction with schooling as a key social institution as well as linking back to the economist roots of many researchers in international development through capital theories already deeply embedded in the field of international development and widely used with the Bank.

In particular, bridging social capital is portrayed as particularly relevant and important to discussions of empowerment because of the transformation of power relations between groups that it can elucidate (Cargo et al., 2003; Watkins et al., 2007; Christens, 2010 & 2012). Building ever-widening circles of relationships is also seen as an important instrumental goal in the field (Christens, 2010). However, bonding social capital does not appear frequently in this literature and should not be given short shrift. Its explanatory power becomes clear when considering the importance in empowerment theory of mobilizing networks (Christens, 2010; Christens & Dolan, 2011; Ospina & Foldy, 2010) and the possibility of facilitating another's empowerment within a group (Pigg, 2002; Kirshner, 2008; Turro & Krause, 2009; Evans, 2012).

It is important to differentiate among types of social capital and the ways that they might be understood, generated, or deployed. Saegert et al. (2001) offer detailed discussions of the different forms of social capital. The distinction between bonding and bridging social capital are particularly important in the field of international development more generally and for the discussion here. Bonding social capital is the web of connections among individuals that hold them together into a more or less cohesive group. Bridging social capital is a relationship that connects individuals or groups that are not members of a single, bonded group to each other. These relationships could result from shared experience or acquaintance. In the case of groups, an individual relationship that overlaps between the two could also be the genesis of bridging social capital between them.

Writing for the *World Bank Observer*, Woolcock and Narayan-Parker (2000) consolidate these definitions neatly:

> Social capital refers to the norms and networks that enable people to act collectively. This simple definition serves a number of purposes. First, it focuses on the sources, rather than the consequences, of social capital (Portes 2000b) while recognizing that important features of social capital, such as trust and reciprocity, are developed in an **iterative process**. Second, this definition permits the incorporation of different dimensions of social capital and recognizes

> that communities can have access to more or less of them. …Accordingly, such an approach allows the argument that it is **different combinations of bonding and bridging social capital** that are responsible for the range of outcomes observed above and incorporates a dynamic component in which optimal combinations of these dimensions change over time. Third, while this definition presents the community (rather than individuals, households, or the state) as the primary unit of analysis, it recognizes that individuals and households (as members of a given community) can nonetheless appropriate social capital and that the way communities themselves are structured turns in large part on their relationship with the state.[8] (Woolcock & Narayan-Parker, 2000, pp. 226-7, emphasis added)

Here, the reference to norms is particularly important for my research since children with disabilities and their parents in Central Asia are excluded from social capital within the family and community by virtue of the severe social stigma attached to disability, in particular disability or developmental delays extant from birth. As a result of this exclusion, parents of children with disabilities in Central Asia have attempted to create social capital through new networks with each other, professionals providing services to people with disabilities, and international actors, often with the goal of shifting or changing the norms that have resulted in exclusion from existing social capital in the first place.

However, the definition that Woolcock and Narayan-Parker put forward (2000) is ultimately insufficient because it skirts the question of power relations in social capital formation. Using Bourdieu's framework of social and cultural capital, Lopez and Stack (2001, p. 32) rightly caution that "to use social assets effectively to combat poverty, we must look at all the directions in which resources and power and cultural meaning travel across social groups, the market, the polity, and civil society." It is important to heed caution from Warren et al (2001, p. 2) that "social capital is not an alternative to providing greater financial resources and public services to poor communities. Rather, it constitutes an essential means to increase such resources and to make more effective use of them" (Warren et al., 2001, p. 2).

[8] Emphasis is my own.

Researchers working with the Bank have made some efforts to address this problem. For example, in a World Bank Working Paper, Avdeenko & Gilligan (2014, p. 5) use social capital as "an umbrella term for a set of individual preferences for social action that are believed to cause better political, social and economic outcomes and the social networks that purportedly support them. In particular, we include under this umbrella four such preferences: willingness to share with the needy, willingness to contribute to public goods, trust, and trustworthiness." The tighter social networks implicit in Coleman's discussion are a more useful theoretical starting point than the looser relationships within the system of social norms implied here (Portes, 2000a). I would go a step further and propose that one of the ways that social capital supports increases and more effective use of resources is by generating the glue that makes collective action, including actions to hold governments accountable, possible for citizen groups and even conceivable for those facing stigma and discrimination.

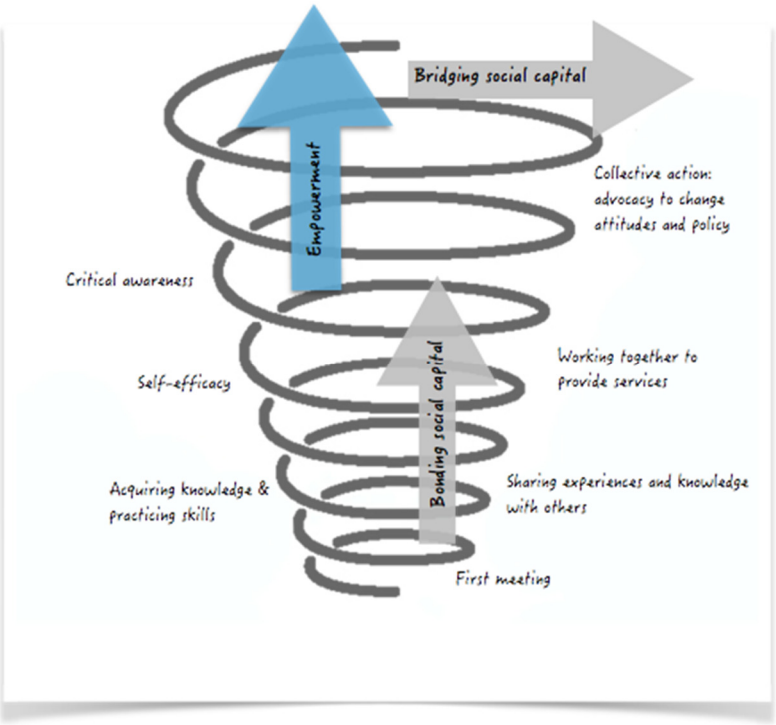
Finally, some researchers have tied social capital more directly to empowerment by expressly focusing on the relationship between social capital and power:

> Power in the context of social capital [is] not just the 'power over' others but the 'power to' act together (Warren 1998). This kind of power can be transformative, creating new forms of cooperation and new solutions to the problems related to poverty ... From this standpoint, we can conceive of building social assets as a way to empower, that is to expand the capacities of poor communities to act to combat poverty and win over new allies (Warren et al., 2001, p. 6)

Perhaps providing a response to the focus on obtaining or increasing access to economic resources often associated with empowerment in the literature of international development, Christens (2012) further warns of the possibility that social capital theory eclipses empowerment in the applied social sciences despite the danger of its own 'rational actor' biases.

Theoretical Framework

Figure 2.3: Empowerment Spiral



The theoretical framework that follows uses a cross-disciplinary representation of the components and paths to empowerment that further refines and extends the model begun by Whitsel and Lapham (2014) based on a synthesis of the cross-disciplinary literature above to include elements of self-efficacy, critical awareness, and social capital formation. This theoretical framework is sketched as a spiral in Figure 2.3. It relates most closely to the field of community psychology, building on Florin and Wandersman's (1990) discussion of the ways that organizing or engaging in collective action can change individuals by increasing their self-efficacy and Christens' (2010) analysis of collective or group self-efficacy in relation to collective action.

The spiral can be roughly divided into three sections. In the bottom section, individuals gain knowledge and practice new skills, gaining the confidence to act and to reach out to others. In the middle of the spiral, they begin to gain critical awareness by understanding that the stigma, discrimination, and lack of power she faces are embedded in the social, cultural, and political contexts they inhabit rather than inherent in themselves as individuals. Finally, individuals come together around these shared experiences and understandings to engage in collective action and to reach out to others in hopes of building a stronger group by pulling new individuals along the spiral with them, forming bonding social capital. Subsequently, the process repeats on a widening spiral until, at some

point, the connections among empowered individuals are sufficiently strong to transfer the process of empowerment to the group as a whole. At this point it is possible for activism and collective action to change attitudes and norms in the dominant population. Such action includes the development of bridging social capital with allies in the dominant population.

This model posits that empowerment is a continuous process that may begin with a very narrow shift, a small change, or a limited interaction spiraling outward in an incremental process of re-balancing power relations through changes in attitudes in both oppressed and dominant groups, capacity to contribute to collective action, and self-efficacy that spurs individuals and groups to begin anew with the pursuit of knowledge, skills and connections to improve their lives, and, in this research, the lives of their children. The section that follows examines each element of the model in greater depth, beginning with the bottom of the spiral.

1) Knowledge, Skills, and Self-Efficacy

In this model, there is an interaction of learning new knowledge and practicing new skills in the development of self-efficacy. An individual who faces severe stigma or discrimination can internalize the negative stereotypes applied by others. This can lead to feelings of helplessness, inadequacy, and shame (Mason, 1990; Pheterson, 1986). These feelings may be intensified if the circumstances of discrimination are new or unexpected. Learning that there are others in the same circumstances who do not view themselves in these negative or fatalistic terms can be the first step toward empowerment. However, in addition to meeting others with a similar identity, further steps toward empowerment require a plan of action based on knowledge and the skill to implement it. For example, a parent who knows that a deaf child can be taught sign language will be in a position to seek out a teacher and develop a plan for learning to communicate. Similarly, a person who knows that he has the right to a pension and where to access the appropriate paperwork will be able to access these funds.

In addition, mastering a body of knowledge or feeling connected to sources of information may be necessary as individuals gain the confidence and other resources to begin exploring their challenges more holistically (i.e. theories of deaf education) rather than troubleshooting one problem at a time (i.e. securing a pension). There is individual effort required and benefit that accrues to each of these actions. Some people may be able to work this out on their own, while others may need information or advice from someone who is more experienced. In either case, small successes build on each other, increasing confidence in the ability to achieve goals in different domains of life, and ultimately building a sense of self-efficacy. Although this can be achieved alone, it is more likely to be built in a supportive environment with others.

2) Social Capital

The supportive environment where self-efficacy develops in this model also supports the beginning of bonding social capital, as individuals interact and build trust in each other. This is particularly important in Tajikistan and similar contexts because there is high potential for exclusion from social capital networks that existed for women prior to the birth of a child with disabilities. First, divorce after the birth of a child with disabilities is common, resulting in a dire lack of social capital for both mother and child. A divorced woman must leave her husband's family, and there is no guarantee that her birth family will take her back or that the broader community will support her. Second, the child (and his/her mother) may be excluded from the social capital that exists within the family even if it stays intact.

The transfer of human capital to the child with disabilities that Coleman describes (Coleman, 1988) may be seriously hindered or largely absent because the family has decided that it does not make sense to invest time in a child who is seen as unable to learn and unable to bring future economic benefit to the family. Likewise, the child's mother loses significant status within the family and may

be subject to abuse or exclusion from the ability to access the social capital of the family structure (Gatling & Juraeva, 2013). It leaves the pair outside the framework of social structures that normally support the upbringing of children in tight-knit Central Asian families, kinship structures, and communities.

Thus, sharing and connecting with others in a similar situation becomes the beginning of social capital formation, as shown in Figure 2.3. Bonding social capital thus becomes an integral element of empowerment that leads to further bonding and possibly bridging connections. By virtue of being thrown together in a similar (sometimes desperate) situation, the mothers can identify with each other and provide mutual support (Portes, 2000a). Coleman's example of social capital among parents sending their children to the same school can also be extended to associations of parents of children with disabilities. Lacking access to social networks in their neighborhoods and often obligated to fight against the social networks of parents of non-disabled children who would exclude their children from the catchment area school or kindergarten, parents of children with disabilities come together with each other to create their own social support networks.

Although social capital theory is entrenched in international development, Grabe (2012) critiqued international development as a field for returning to a more individual concept of empowerment by stressing agency and choice that, while acknowledging discrimination for some, has not paid sufficient attention to the importance of complicated and specific social contexts in the process of empowerment. This is seen as one of the strengths of community psychology's approach to empowerment because "the transformative power that empowerment theory seeks to promote is developed and exercised in and through relationships, as well as emotional, cognitive and behavioral processes" (Christens, 2012, p. 117). However, Christens (2012, p. 116) also noted that empirical studies in the field of community psychology have focused on empowerment often make use of

relational frameworks, although there is still need to incorporate these at the theoretical level. Others allude to this as well. For example, Kieffer (1984) and Peterson and Zimmerman (2004) discuss the importance of collaboration and collaborative relationships. Alliance building (Cargo et al., 2003; Christens, 2010; Pigg, 2002; Peterson & Zimmerman, 2004; Russell et al., 2009) and ability to access social networks (Fedi et al., 2009; Laverack, 2006; Peterson & Zimmerman, 2004) are also identified as essential in empirical studies. This is a clear need in the field, and there are a great number of relational frameworks that could be incorporated into a theoretical model of empowerment.

The framework of bonding and bridging social capital provides a clear and compelling way to discuss the relationships within a group, in this case women facing the stigma of having a child with a disability, and between groups. Thus, the relationships, including hierarchies and distribution of power, can be elaborated among members of this discriminated group as well as between members of this and other groups, such as their extended families, communities, etc. Others working in the field of community psychology have also relied on social capital for similar reasons. At the most basic level, collaborative competence, or the ability to make connections and work with others, is understood to be an important aspect of any relational framework of empowerment (Kieffer, 1984; Foster-Fishman et al., 2001; Russell et al., 2009; Ginwright, 2007; Speer, 2000 & 2008). This meshes well with the common definitions and typologies of social capital in sociology. In particular, the idea that social relationships could be sought specifically for the social capital that they create is a useful idea for framing this research.

There are three sets of potential linkages that develop within this model. First, solidarity within the group of mothers with similar experiences, needs, and concerns creates a bonding social capital (Allan, Smyth, l'Anson, & Mott, 2009; Bates & Davis, 2004). According to Portes (2000a, p. 8), "the altruistic dispositions of actors in these situations are not universal but are bounded by the limits of

their community. Other members of the same community can then appropriate such dispositions and the actions that follow as their source of social capital." As in Coleman's example, this is often the work of a small number of people initially, like the three founding mothers of an association for parents of children with autism, *Ashyk Alem,* in Kazakhstan (Markova & Sultanalieva, 2013), but it benefits many more. In Tajikistan, there is evidence of bonding social capital within the associations as mothers are able to gain access to knowledge about disability, specialized education and other services within the association, and mutual emotional support from others facing the same challenges.

Second is the formation of bridging social capital (Anthias, 2007; Bates & Davis, 2004) that would link the networks of mothers and children in Tajikistan to their peers in the abled community. Due to the stigma associated with disability and the family norms that may prevent women from talking about the activities of the group publicly, this link may be much slower to develop. However, there is some evidence that the development of bridging social capital is occurring as the associations hold public events and teachers become more confident admitting children with disabilities to their classes (Whitsel & Kodirov, 2013). This comes about as mothers advocate through and with the support of parent associations for their children to be included in classrooms with their peers and teachers have successful experiences. The dynamics within the classroom and the extent to which bridging social capital is formed between the school community and the above-mentioned parent associations merits further research.

Other researchers working in different geographies have made similar findings. For example, Balatti and Falk (2002) working in Australia found that "participants reported that increased networking and increased self-confidence led to community action, which in turn led to community benefits" (p. 291). However, it cannot be only the marginalized community that seeks to develop bridging social capital. There must also be allies in the majority community who are ready to connect

to the forms and structures of social capital embedded in their culture and struggle. Thus, these allies in both groups become an important part of the initial bridge linking different groups (like parents and specialists in the case of children with disabilities) (Lopez & Stack, 2001). This brings us back to the earliest conceptual roots of social capital. Farr (2004) notes that trust has eclipsed Dewey's concept of sympathy in subsequent definitions of social capital as a concept. Dewey's understanding of sympathy encompassed compassion, empathy, and a sense of inter-connected welfare. This is significant for a synthesis of social capital and empowerment from a social justice perspective. "Where social capital is denied, deprived or absent, shared public work via active networking in associations is the only solution or amelioration available" (Farr, 2004, p. 16).

Finally, there is a third set of linkages that create a source of social capital for some of the parent associations mentioned here. That is the link between these associations as NGOs and international actors. Once their relationships are formalized in a legal entity, such as an association, these groups of parents can access social capital from similar groups in other countries, other networks and organizations concerned with issues of disability (advocacy groups, professionals and service providers, disabled people's organizations), and philanthropic or international aid organizations. These relationships can be leveraged for access to information, funding and other forms of direct support, and increased legitimacy in the home community through participation in transnational advocacy networks (Mundy & Murphy, 2001) around the rights of people with disabilities and the right to education. These links represent both bonded social capital, as many of the international groups involved in disability issues began in similar circumstances of exclusion, and bridging social capital that helps to link these groups to the community of policymakers. This is particularly true of bridging social capital sought with the end goal of transforming disability from a private challenge to a public question thus bringing disability into a human rights framework rather than a charity model.

It is also important to note that all parents of children with disabilities may not have access to this newly created social capital despite efforts to reach out to them. They may still be quite marginalized within their families and communities. Type of disability, proximity to populations centers more likely to host a formal or informal group, ethnicity, economic status may all be factors influencing access to social capital as well. These all merit further research in the context of Central Asia and Tajikistan.

3) Critical Awareness

As the process approaches the top of the spiral, critical awareness is an essential step toward empowerment. Without a firm understanding of the ways that social structures, including prejudice and discrimination, affect individuals combined with empowerment's internalized sense of one's human rights, there cannot be concerted action, whether individually or collectively, to change oppressive norms or structures. It is impossible to work toward changing something that is not understood as a problem's source. Furthermore, it is essential to believe that you have the right to advocate for change to social norms and structures that are unfair or unjust. At the same time, it is important to remember that changes in power remain highly contextual in form and pace. It is vital not to mistake the lack of a clearly stated agenda to change power relationships for a lack of critical awareness.

In a semi-authoritarian environment like Tajikistan, pushing too quickly could result in a major setback or even direct physical danger. Riger (1993, pp. 287-88) notes this as well, although she does not use the terminology of critical awareness, using the example of two rape survivors' differing decisions whether to prosecute their attackers to illustrate that the "actions resulting from personal empowerment can be opposite depending on personal circumstances, social status, and culture." Unfortunately, she uses this example to dismiss personal empowerment as an indicator of potential

transformation of power relationships rather than seeing an empowerment process with steps that include the individual as well as the social.

This is the reason for envisioning empowerment as a process that spirals outward, growing in magnitude without a pre-defined end point, with critical awareness as a key component. The first steps on a transformative journey may not look significant or even positive to an outside observer. The rate of progress may also slow or quicken over time. Critical awareness can also develop with an individual or within a group, contributing to bonding social capital, and inspiring attempts to build bridging social capital when empowerment of group members turns their focus outward to seek change.

This trajectory has been repeated within parent groups supporting parents of children with disabilities. Within the field of community psychology, for example, there are numerous studies focused on the empowerment of vulnerable groups who are receiving a social service intervention (Cochran, 1992; Delgado-Gaitan, 1991 & 1994; Hyung Hur, 2006; Leung, Tsang, & Dean, 2011), which includes parents of children with disabilities (Itzhaky & Schwartz, 2001; Nachshen & Minnes, 2005; Samadi, McConkey, & Kelly, 2013). First, parents seek support from professionals and each other when learning about their child's disability. In their initial stages, parent groups may define their role solely in terms of providing emotional support to other parents and sharing experiences. In time, some parents may gain significant expertise in supporting the development of children with disabilities, becoming professionals or experts in their own right. Groups of parents may evolve to provide their own services, particularly in contexts where services are unavailable or substandard.

The empowerment of parents to participate actively in the services supporting their children is characterized positively in this literature. McCammon, Spencer, and Friesen (2001) write persuasively about the multiple roles that parents of children with serious emotional problems can play, including their potential to educate and train professionals, students, and other family members.

Citing examples in Illinois, Pennsylvania, Maryland, and Rhode Island, Ignelzi & Dague (1995) make the case that family members of children with emotional and behavioral challenges have long been providing services to their own and other families that include self-help groups for emotional support and information exchange as well as actually delivering or coordinating service provision. They further characterize the 'next step' in parent involvement as providing direct services for fees, including as mentors, case managers, early intervention workers, advocates, in-home support staff, respite providers, service planners, and managers of family cash grants (McCammon, Spencer, & Friesen, 2001), similar to the reported development trajectory of the associations in this study (Lapham 2013).

In studies of families affected by mental illness in children, Heflinger and Bickman (1996) agree that the definition of empowerment includes increasing caregiver knowledge about topics such as ways that the mental health system functions, parent and patient rights, and general knowledge of mental illness, evolving to include the development of skills, like communication and identification of helpful resources. These steps are necessary but on their own are not sufficient for empowerment. "Merely enhancing a sense of personal control, when there is no actual control, typically supports the status quo or promotes conflict. Therefore, empowerment strategies must also promote a process that increases access to resources; enhances ability to influence people, organizations, and policies" (McCammon, Spencer, & Friesen, 2001, p. 105).

Although this trajectory is noted, it is not explicitly connected to critical awareness or connection to others through the development of social capital. These two links are essential to understanding parent individual and collective action beyond their interaction with professional services, including a shift in understanding from a charity model of disability to human rights (Groce 2002). First, parent groups may also develop advocacy and mediation services that push the existing systems of education, health, social protection to function at the fullest extent of their mandates. As

critical awareness develops within the group and combines with members' sense of self-efficacy and stores of social capital, the parents are able to envision changes in social norms and structures with the potential to make them and their children more fully included in their communities and have the capacity to work toward those changes together (See Woodruff, 2016).

Finally, it is essential to return to the question of measurement in order to apply this theoretical framework by understanding in what constitutes progression along the spiral of empowerment in a rigorous way. A single research project is not enough to fully test the theoretical model. Rather, it is a first step to understanding whether it has potential explanatory power as a framework and to suggesting questions for further research. In this sense, the study continues work begun by Grabe (2012) to bring together frameworks from international development and community psychology in order to provide empirical analysis of women's empowerment in the context of globalization.

Through the course of the three inter-related cases, I will draw on this theoretical framework to respond to questions about the interaction between empowerment, social capital, and advocacy of educational opportunities for children with disabilities. This has the potential to make a significant contribution to the literature because the vast majority of studies exploring social capital are based in the United States with a much smaller number in Europe and only a handful in developing countries. The literature on empowerment is broader with more research focused on developing countries as aid agencies have engaged significantly with the concept. However, Tajikistan and Central Asia more generally remain under-studied. The next chapter explores the methods for the case studies and findings that follow, examining the implications of choices between quantitative and qualitative methods, the ethical considerations of working with mothers of children with disabilities in Tajikistan, and describing the process of data collection and analysis as it took place in the reality of limited time, resources, and political context.

Chapter 3 : Methods

This chapter provides a detailed description of how this research was designed and implemented. It begins with a discussion of the choice of qualitative methods and Robert Stake's multiple case study approach in particular, which was used to describe and analyze parent associations in three distinct places, and the ethnographic approach adopted to develop the cases. A description of the protocols for interviews and focus groups developed for the study follows. This includes references to literature on research methods and direct work with families affected by disability, focus groups and group dynamics, and the context of research in Tajikistan. A discussion of the additional data sources used in the study follows, which includes observations, public documents and gray literature, and public presentations.

After establishing the methods of data collection and the sources of data, this chapter discusses the collation and analysis of data used to develop the case studies in Chapter 4. This section includes a discussion of the ethical considerations for researching this sensitive topic, the tools and protocols that the researcher developed for managing, coding, protecting, and analyzing the data, as well as a detailed map of the research instruments and the sample of respondents who participated in the study. Finally, I turn to the discussion of triangulation and verification of analysis through member checks, and the limitations of the study.

Designing the study

A great deal of research using empowerment and social capital as frameworks for analysis, particularly in the field of international development, uses quantitative methods rather than qualitative methods. The purpose of this research study is to apply the theoretical framework developed in Chapter 2 to an under-researched geography in hopes of saying something important about both. Therefore, it is

useful to devote some discussion to the appropriateness of qualitative methods for the theoretical framework in this particular project and context. Quantitative research could be used to apply a tested theoretical framework of empowerment and social capital to a new place or population, although quantitative approaches, particularly those that use large datasets for comparisons, can have their own pitfalls, as demonstrated in the studies described in Chapter 2. There is a tendency to force the parameters of empowerment to overlap with datasets that are already available or easily collected.

Another pitfall of quantitative research is that it can only be as robust as the datasets analyzed. In Tajikistan, classification of disability is contested and confusing with different ministries and agencies often using different classifications and thus collecting information that is not appropriate for longitudinal or comparative analysis (OECD, 2009). Furthermore, the quality of data that is collected is suspect due to lack of resources for the State Institute of Statistics under the President of Tajikistan (TajStat) (Lapham, 2017). Finally, the data that is collected is focused on demographics and enrollment or usage in existing state services, making it difficult to construct datasets that speak to outcomes or experiences within these services over time in a reliable way. Tajikistan last participated in UNICEF's MICS in 2005 and in USAID's Demographic and Household Survey in 2012. While providing some useful background information, this survey does not include information about disability or childhood except at the most superficial level. With the exception of data on home births, little in these datasets relates to motherhood.

However, even if comparable and reliable datasets were available, qualitative research would still be the stronger choice for this dissertation because the quantitative compilation of indices and composite indicators of empowerment and social capital run the risk of disconnecting theory and its contextualization and operationalization (Adam & Rončević, 2003). Once research on empowerment shifts its focus from the individual level to the group or community level, qualitative research methods

are necessary to contextualize the processes of empowerment and the characteristics of the types of organizations or groups that empower (Maton, 2008). Psychometric research on individual empowerment does not necessarily aggregate to a group nor does it explain the process of empowerment – a key focal point of this research.

A qualitative approach allows the development of context-specific indicators and a more thorough exploration of the nuanced interaction between empowerment and social capital that is appropriate for developing this theoretical framework. Failure to identify the constituent processes of empowerment and the links between them is a noted gap in previous research on empowerment (Grabe, 2012). Thus, this dissertation uses a qualitative approach in hopes of surfacing the contextual details that form the processes of empowerment in this setting as well as some of the links between them. Maxwell (2005, pp. 2-3) defines qualitative research as:

> Research that is intended to help you better understand (1) the meanings and perspectives of the people you study – seeing the world from their point of view … (2) how these perspectives are shaped by, and shape their physical, social, and cultural contexts; and (3) the specific processes that are involved in maintaining or altering these phenomena and relationships.

This is particularly important for this research because the ways that people associate and form connections as well as the benefits that they derive from these connections – the essential basis of social capital and a constituent part of the model of empowerment – is a highly context-specific process. A qualitative approach allows for interrogation of social capital formation as an ongoing process (Jarrett, Sullivan, & Watkins, 2005; Falk & Kilpatrick, 2000). It also allows for greater contextualization because so much of the theoretical and empirical work defining the concepts of empowerment and social capital have emerged from Western contexts. Rappaport and Zimmerman both worked in the United States, although they are both deeply concerned with minority and marginalized communities. Researchers in the field of community psychology have only begun to apply empowerment research to international and developing country contexts (Grabe, 2012;

Christens, 2013). Coleman and Putnam both worked in the United States and Bourdieu worked in France.

In designing this study, I understood that applying these ideas to a non-Western and under-researched context like Tajikistan required significant adaptation of the ways that indicators are structured as well as consideration of the differences in family, friendship, and other social structures. An intensive interview methodology with an ethnographic approach was chosen to provide the richness and flexibility of observation necessary to gather and triangulate this information:

> When researchers do ethnography, they study a culture's relational practices, common values and beliefs, and shared experiences for the purpose of helping insiders (cultural members) and outsiders (cultural strangers) better understand the culture (Maso 2001). Ethnographers do this by becoming participant observers in the culture. (Ellis, Adams, & Bochner, 2011, pp. 275-6)

The use of some of the tools of ethnography in developing this research cases also "allows researchers to investigate social groups or specific fields from the inside so that unseen social capital or the unacknowledged mode of collective action can be uncovered" (Wong, 2007, p. 51). Given the stigma attached to having a child with a disability in Tajikistan, it was an act of bravery for these mothers to associate with one another in the building of social capital. This process took place in the small spaces that they could negotiate within their families and communities, epitomizing the initially unseen collective action that Wong describes.

Furthermore, the structure and detailed management of case development was important to ensuring that this research project resulted in an informative account of empowerment and social capital formation among parents of children with disabilities in Tajikistan. Within that structure, focus groups and interviews informed by the tools of ethnography proved to be the methods most suited to gathering information flexibly and comprehensively enough to build each case. The complexity of the relationships studied and the importance of the relationship between context and social capital

demanded this type of observational, conversational approach.

A more structured approach to data collection would have risked missing important phenomena through the bias of preconceived ideas that could have been imbedded in more formal research survey instruments. However, a purely ethnographic approach would have required observations in private spaces, like the homes of research participants, which would have been very difficult to access because the entire extended family present in that space would have had to consent to participate in the research. Otherwise, reporting such observations would be an unethical breach of the privacy and discretion expected of guests in Tajik culture.

As a result, I chose a combination of the methods associated with qualitative research, including interviews, focus groups, and observations, with an ethnographic approach in designing this study. These methods supported gathering data that responds to the research questions and extended understanding of the relationship between empowerment and social capital formation in an under-studied context. This combination of qualitative methods also allowed research participants to tell their own stories. Rather than simply gathering information about children's disabilities and educational placement, this study recognizes that people with disabilities are often invisible in Tajikistan. I seek to relate the experiences of families of children with disabilities and the parent organizations they have created with respect in a way that will be empowering to them.

Maxwell (2005, p. 79) tells us that "there is no such thing as 'inadmissible evidence' in a qualitative study [because the researcher herself] is the research instrument. Data in a qualitative study can include virtually anything that you see, hear, or is otherwise communicated to you while conducting the study." This is particularly relevant to this study because of my personal and professional connection to the historical development of the parent groups being studied.

Reflecting on this relationship, as a foreigner in Tajikistan, it was not possible for me to

become a full-fledged insider, particularly in the dynamics of family relationships and vulnerability that I could only observe albeit at a close distance. On the other hand, I have worked for the Open Society Foundations with responsibility for education-related grant-making since 2004. The Open Society Foundations' Education Support Program and OSI Tajikistan have been supporting the development of a coalition of associations of parents of children with disabilities since 2009. Furthermore, the Open Society Foundations hoped that the empowerment of individual parents within these associations would lead to increased social capital among parents of children with disabilities. This, in turn, would create the networks necessary to advocate for change in the education and social inclusion of children with disabilities in broader Tajikistani society.

Reliance on personal experience for the formulation of research has advantages and pitfalls. In some sense, it is impossible to fully eliminate the biases of personal experience in defining research (Ellis, Adams, & Bochner, 2011; Howe & Moses, 1999), so acknowledging them transparently rather than claiming an impossible objectivity was an important first step in developing rigorous methods for this research:

> The methodology of social research must … seek out and listen carefully to 'voices' embedded in their social context to gain a true understanding of what people are saying and why they do what they do. And dialogue itself has consequences: Beliefs, culture norms, and the like are not just there, waiting to be uncovered, but are negotiated and "constructed" via the interactions among researchers and those they study. (Howe & Moses, 1999, p. 32)

A fluent Russian speaker and student of Tajik language, I was based in Central Asia, dividing my time between Kyrgyzstan and Tajikistan from 2004 through the summer of 2012, spending significant amounts of time in Tajikistan, particularly from 2004 to 2009. During this time, I was engaged in direct work with the parent associations that participated in the study. In 2012, I moved to Istanbul but remained responsible for grant portfolios in Tajikistan until 2016, although I transferred primary responsibility for work with the network of parent associations to a program officer under my

supervision at the end of 2014. Indeed, this experience motivated the location and framing of the research questions.

By acknowledging a personal and professional connection to this research topic, I accepted the burden of analysis through careful triangulation of data and continued interrogation of my findings (discussed in detail later in this chapter). Over the year prior to the fieldwork for this dissertation, I worked to distance myself from the Open Society Foundations' support to the Coalition and constituent parent groups by engaging another staff member as the primary point of contact. This helped the research participants see me in a new role as a researcher. It also allowed me to see them with fresher eyes. However, I relied on frequent checks between the influence of my previous experience on my assumptions or expectations, which are well-documented in my funding recommendations to the Open Society Foundations and my own field notes from previous visits, and the data that emerged from interviews, focus groups, and observations.

Organizing the study: Multiple case study analysis

The research questions in this study go beyond the individual to compare and examine choices about collective action across groups. The central research question asks about the circumstances that allow and motivate mothers of children with disabilities to come together in support of each other and their children. At the outset of this research in 2015, there were 28 associations of parents across Tajikistan. It was essential to identify an appropriate method of comparison that would still provide the space to present individual responses and actions, clearly in context, while at the same engage in a cross-case comparison. The research builds on Robert Stake's (2006) multiple case study approach by selecting three cases and developing each of them based on discrete phenomenon to facilitate comparison. Stake's (2006) concept of a quintain has provided an appropriate organizational structure

for this task:[9]

> A multi-case study starts with recognizing what concept or idea binds the cases together [into a quintain]. A quintain is an object or phenomenon or condition to be studies – a target but not a bull's eye [like a repertoire in music]. This quintain is the arena or umbrella for the cases to be studied. Sometimes this concept needs to be targeted; usually we target the quintain that provides the binding concept. The cases to be studied may each have a different relationship with the quintain. Some may be model cases, and others may have only an incidental relationship. If other considerations are satisfied, cases will be selected because they represent the program of phenomenon. An important reason for doing the multi-case study is to examine how the program or phenomenon performs in different environments. (Stake, 2005, pp. 83)

In this case the binding principle or umbrella is the experience of raising a child with disabilities in Tajikistan with the mutual support of other parents in an association. Case studies developed with qualitative methods have the potential to capture the experiences of individuals participating in a given program or phenomenon are particularly appropriate within this discipline and in response to these research questions.

> A scientific discipline without a large number of thoroughly executed case studies is a discipline without systematic production of exemplars, and a discipline without exemplars is an ineffective one. Social science may be strengthened by the execution of a greater number of good case studies. (Flyvbjerg, 2006)

Building from the context of personal and professional experience, this study developed three case studies that describe the experience of raising a child with a disability in Tajikistan and explore the changes that take place when social capital is built through participation in parent groups. Each case study explores the relationships built through participation in parent groups and their experiences as a phenomenon with clearly delineated boundaries. This is important because, "if there is no end, actually or theoretically, to the number of people who could be interviewed or to the observations that be conducted, then the phenomenon is not bounded enough to qualify as a case" (Merriam, 1998,

[9] Robert Stake developed the text on multi-case analysis referenced here with funding from the Early Childhood Program of the Open Society Foundations as part of an initiative to document the development of the Step by Step Program.

p. 28). These case studies are rooted in a specific time, place, and group of people. They are sufficiently bounded to allow the method to be applied effectively in answering the questions how and why regarding parent empowerment and social capital formation in the complex environment of Tajikistan.

Furthermore, many of "the variables are so embedded in the situation as to be impossible to identify ahead of time" (Merriam, 1998, p. 32), which further supports the use of the case study method for this research. This research ventures into territory that is not heavily charted in the existing literature. An ethnographic approach to the multiple case study method has offered the necessary flexibility to adapt research instruments and follow-up as participants raise new questions or provide information that could be unexpected. Emerson, Fretz & Shaw (2011) explain:

> Ethnographic field research involves the study of groups and people as they go about their everyday lives. Carrying out such research involves two distinct activities. First, the ethnographer enters into a social setting and gets to know the people involved in it; usually, the setting is not previously known in an intimate way. The ethnographer participates in the daily routines of this setting, develops ongoing relations with the people in it, and observes all the while what is going on. Indeed, the term 'participant observation' is often used to characterize this basic research approach. But, second, the ethnographer writes down in regular, systematic ways what she learns while participating in the daily rounds of the lives of others. (p.1).

This study does not provide a pure ethnographic approach because I used semi-structured interviews and focus groups in addition to observations of the daily life and activities of the parent associations. However, the study draws on ethnographic elements because the research questions focus not only on individual empowerment but also on the relationships, connections, and decisions to act among members of group. Ethnographic observation provides important information about group dynamics and decision-making that serves as a check to information provided during interviews and focus groups. Ethnographic observation and continuous review of my notes also inspired questions to be followed up during interviews and focus groups as well as the review of documents.

Finally, Stake (1978, pp. 5-6) claims that "case studies will often be the preferred method of research because they may be epistemologically in harmony with the reader's experience and thus to that person a natural basis for generalization. … What becomes useful understanding is a full and thorough knowledge of the particular, recognizing it also in new and foreign contexts." By studying a specific set of mothers and children in the context of their parent organization affiliation, communities and school, the case study method gave me the opportunity to observe the relationships and connections essential to understanding social capital networks. At the same time, the in-depth interviews and other forms of qualitative data collection presupposed in the development of each case allowed me to interrogate processes of empowerment and social capital formation in the limited amount of time available for this research while making use of my prior experience in Tajikistan.

This research used a multiple case study approach in order to allow each of the cases to be developed based on discrete phenomenon and to facilitate comparison among them. These three cases were chosen because they are roughly representative of the diversity within the coalition of parent associations. Both of the associations that focus on a specific type of disability are located in Dushanbe and are probably destined to remain in urban areas because they offer the concentration of population to support an association of this type. The associations located in rural areas tend to be more service-oriented and support parents of children with any type of disability (Lapham, 2013).

In conducting multi-case analysis, it is important to select the right number of cases, to respond to research questions. Stake (2005) advises identifying between four and ten cases so that there is enough information to identify trends or binding themes across cases while maintaining a research project of reasonable scope for implementation. These three cases were chosen because they are roughly representative of the diversity within the Coalition of parent associations, spanning urban and rural areas, associations dedicated generally to disability vs. focused on a specific condition, and

areas with differences in population structure and culture.

The advantage of the multi-case approach is the possibility to compare empowerment processes and social capital networks among different associations. This allowed for conclusions about my research questions and theoretical framework as well as the formulation of future research questions for the associations throughout the country. It was also possible to add some quantitative analysis to data gathered from parents who are members of each association, as described in the chapter on research findings. However, the unit of analysis is the association itself; so, the limited sample size may pose limitations to generalization from this research.

The descriptive multiple case study approach allowed me to look at three distinct but related phenomena of parent-led or instigated inclusive education through the work of three different but representative types of parent groups. Studying these groups and the mothers who participate in them allowed me to draw conclusions about the empowerment and formation of social capital among mothers of children with disabilities in Tajikistan and to see differences by comparison of groups in different places or with slightly different missions. This method also provided a structure for my research and fieldwork that was sufficiently flexible to capture "late-emerging issues" and important but unanticipated themes (Stake, 2005, p. 30). As discussed above, I developed three cases:

A. Urban Area – Specific Disability Group: The first of these is the non-governmental organization IRODA, which provides support for children with autism. IRODA is located in School #72 on the outskirts of Dushanbe, the Soviet-created capital of Tajikistan for the past 80 years. Dushanbe is the center of political life and was hotly contested during the civil war. IRODA was founded in 2008 by the mother of a child with autism and formally registered in 2011. IRODA has grown from a small support group to a respected organization providing a variety of services to families of children with autism, including behavioral analysis and therapy, school preparation and preschool groups,

counseling services, referral services, after-school activities, and support to teachers. IRODA sometimes raises funds to operate national programs, in particular supporting other associations as they gain members affected by ASD.

Research in Dushanbe also yielded a change in the research plan. While working with the members of IRODA, I was struck by the similarity of their path to learning that their children were on the spectrum – typically a behavioural regression around 12-18 months of age followed by an odyssey of doctor's visits and misinformation. This experience seemed important and unique, leading me to wonder whether the paths to empowerment through development of social capital and collective action would be different for parents whose children were identified as having a disability in the delivery room. To further explore this question, I expanded the case study in Dushanbe to include SiDa, the association of parents of children with Down Syndrome. In addition to providing material for comparison, this additional data collection also proved an important source of triangulation for accounts of the history of the Dushanbe associations' development.

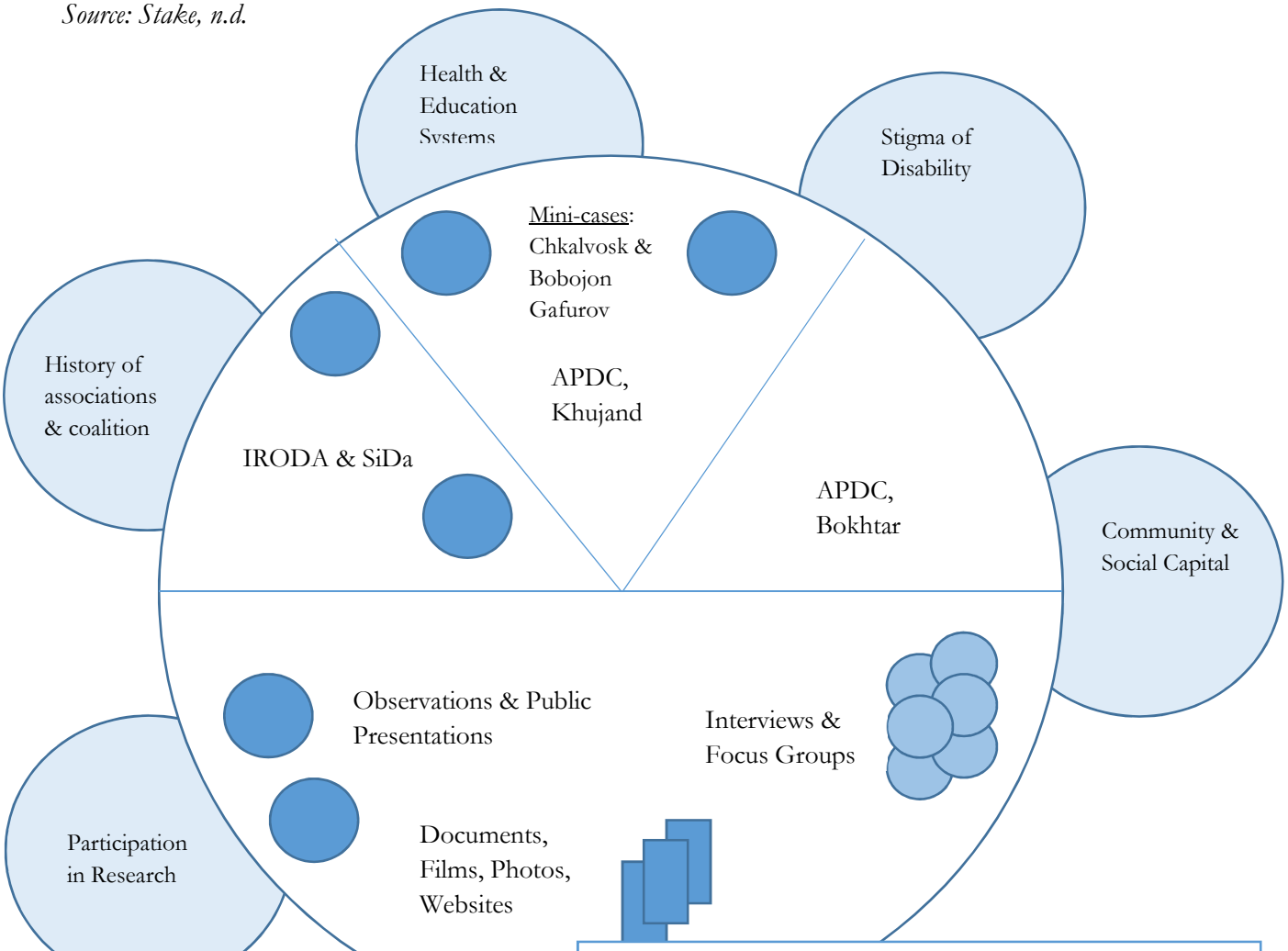
B. Urban Area – No Specific Disability Group: Khujand is the administrative center of Soghd veloyat, a northern region separated from central Tajikistan by the Fan Mountains. Historically, Khujand was much closer and more accessible to the ethnic Tajik areas of Uzbekistan around Samarkand. It was largely untouched by the civil war. The second case study, based here, is the Association of Parents which is based in Khujand and founded in 2008 and formally registered in 2010. This center provides support services to children with disabilities, works with parents when they have questions related to their children's disabilities, rights or available services, and served as coordinator of the coalition as a whole in 2016. They have also devoted significant energy to setting up additional parent groups in areas that are challenging to reach because of deficiencies in the public transportation network.

During the course of my field work, it became apparent that setting up and supporting these additional groups was a core part of the mission of the Khujand association. The association staff often worked with the NGO that supported them to incubate new parent groups in a similar way. The relationships between the Khujand group and the newer parent groups thus formed an important part of their story. This led me to add data collection focused on the newer, daughter associations in Chkalovsk and Bobojon Gafurov. Table 3.3 shows the distribution of interviews and focus groups that allowed me to provide mini-cases within the Khujand case study to surface themes of network expansion, collaboration, and outreach to new members within the framework of this case.

C. Rural Area – No Specific Disability Group: The third is a small association of parents in Bokhtar district, Khatlon oblast. This association of parents registered formally in 2009 and has a room free of charge from a friendly organization with a World Bank agriculture project. However, education is a priority for the association, and they are working with department of education to get office space in a school. Their main activities include helping parents register for social benefits, consultations with children, and help in registering children for school. Among the association members, they have 16 children in mainstream primary school. Bokhtar is located 7 km from Kurgan-teppe in an area that was on the frontlines of the civil war. It is also an area that has seen forced in-migration from the historically conservative Rasht Valley during Soviet times.

Figure 3.1 is taken from Robert Stake's work and provides an approximate illustration of the interaction among the three cases as well as the sources of information and pathways for synthesizing it into research findings. It shows areas or bodies of knowledge that sit outside the cases but overlap with them to provide context that frames each case and the study as a whole in space and time.

Figure 3.1: Multicase Quintain
Source: Stake, n.d.



Theoretical Issues

Evolution from exclusion to recreating social connections and activism within a framework of empowerment

Research Questions – Information

1. Under what circumstances do mothers of children with disabilities engage in collective action to support their children?
    a. How do the connections between the mothers evolve in different geographical and organizational settings of the cases?
    b. From the perspective of mothers of children with disabilities, what type of experiences empower them to take collective action?
2. What types of initiatives are emerging from the parent groups in the three cases?
    a. When and how do they emerge? To what extent are they internally or externally driven and supported?
    b. From the perspective of mothers of children with disabilities, how do these initiatives affect their situation within their extended families and/or communities?

The diagram above provides a visual representation of the construction of a multi-case analysis. The circles emerging along the edges represent the context of the cases that is common throughout. These include the cultural stigma of disability and giving birth to a child with a disability, the systems of education and healthcare in Tajikistan, the sense of community and social capital that exists across the associations, and the shared history of developing associations and increasing closeness within a national coalition. The location and primary focus of each case is represented by one inner triangle. Mini-cases are represented by the smaller circles within these wedges.

Each case was developed with the research methods and evidence described in the lower half of the large circle. Two of the cases yielded smaller, mini-cases. In Dushanbe, I studied two associations focused on different types of disability – autism and Down Syndrome. In Khujand, I gathered information from the older, central parent association as well as the two newer associations that grew from this group in Chkalovsk and Bobojon Gafurov. Interviews, documents, and observations are related to each case but also have an independent space where they provide information about the processes of empowerment and collective action across the entire sample.

Table 3.1: Research activities and sources of information

Research Activity	Description	More information
Interviews	Semi-structured interviews with 75 association members and 14 key informants. Key informants include people who support the associations but do not define themselves as members and who do not, themselves, have a child with a disability.	Table 3.3 Appendices 4 &7
Focus Groups	10 focus groups with association members and leaders	Table 3.3 Appendices 4 & 7
Observations	5 days each in Bokhtar and Khujand and 11 days in Dushanbe observing activities in each association as well as the full day May 6, 2015 attending the annual Coalition forum.	Table 3.6

Surveys	Brief demographic surveys collected from the 75 association members interviewed and 31 surveys completed by association directors with questions about organizational structure, service and programs provided, and membership in the Coalition.	Table 3.6 Appendix 9
Documentary analysis	Public documents including web sites and annual reports. Unpublished documents, including grant proposals and reports, OSF staff trip reports, consultant reports, and budgets.	Table 3.4 Appendix 4

The sections that follow describes in detail the development and implementation of protocols for each type of research activity.

Collecting data: Designing interviews and focus groups

In order to develop a rigorous approach to my research questions, I reviewed models and instruments that other researchers have used to answer similar types of questions with populations as comparable as possible in other contexts. In some cases, this has been difficult because of the lack of empirical research in Central Asia. However, there are some measures, questions, research instruments validated in the West that could be adapted. The research studies of Katsui (2005) and Harris (2004) was useful in contextualizing these instruments to propose a possible profile or set of characteristics that mothers who become advocates for their children with disabilities are likely to possess and how they might begin the journey of empowerment and social capital formation. Finally, my own long experience working in Tajikistan since 2004 and with issues of inclusive education in Central Asia since 2008 added to the validity of this research (Maxwell, 2005, p. 110).

One possible measure of whether mothers believe that their lives have been improved through participation in these associations is the level, and hopefully reduction, in their perception of caregiver strain. Brannan, Heflinger and Bickman (1997) developed a 21-question form to self-report the level of strain that they experience as caregivers for family members with mental illness. I looked specifically

at these instruments because the stigma and difficulty accessing services for people with mental illness in the West is more similar to the challenges of having a child with disabilities in Tajikistan, which makes this comparison more fitting than using measures of caregiver strain for children with disabilities.

The parameters of the questionnaire that they used include those listed in the table below (Brannan, Heflinger, & Bickman, 1997, p. 3), which can loosely be categorized contributing to empowerment through personal well-being, through the well-being of the individual within the family, and the development of bonding social capital. Since these parameters were originally meant to measure caregiver strain, they have been reformulated for the purposes of this research in the positive to indicate positive change.

Table 3.2: Feelings of empowerment and social connection

Personal well-being	Well-being in the family	Bonding social capital
feeling [less] sad or unhappy	feeling [less] embarrassed	feeling [less] socially isolated
feeling [less] tired or strained	relating well to child	[less] disruption of family relationships
[not] feeling guilty about the child's illness	feeling [less] worried about the child's future	[less] disruption of family's social activities
[less] feeling angry or resentful toward child	[not] missing work or neglecting other duties	feeling [less] worried about the family's future

In order to gather information about social capital, including feelings of trust and safety in the group, among the mothers within each of the three cases, I used a modified framework of questions

originally used by Bates and Davis (2004, p. 196) to define parameters of social capital in rural communities in the United Kingdom in conjunction with some of the questions from Brannan, Heflinger and Bickman. My research instruments developed a profile or set of characteristics common to the women who have become advocates for their children and explored the nuances of family circumstances, social status, and the timing and intensity of membership in the group to explore the formation of social capital and empowerment of these women.

Colette Harris' (2004) work on gender identity in Tajikistan was used to further contextualize this framework to make sure that the questions capture similar phenomena in Tajikistan, a very different and little-researched geography. In short, I started by building a demographic profile of the mothers interviewed that includes age and seniority within the family, social standing of natal and marriage family, structure of the household (presence of husband, number of generations under one roof or close by), and level of education and employment status. The sample provided enough information to compare responses and explore how this profile might differ for founding and subsequent members of the group, which was informative in developing the cases and responding to the research questions.

A full set of research instruments is available in Appendix 7. Interviews varied in length from 0 minutes (for one woman who did not wish to participate after hearing the questions) to 51 minutes with an average duration of about 17 minutes in Bokhtar and Khujand, and 25 minutes in Dushanbe. A complete list of interviews is provided in Appendix 4 with the location, duration, and language used. During the interviews, I did not probe past the comfort level of the respondent, which meant that some interviews were shorter and that not all questions were fully answered in every interview. In analyzing the findings, I note the number of interviews where a response to a specific question (e.g. about the benefits of joining an association) was answered. Questions where the interview pool did not yield a sufficient number of responses to draw a rigorous conclusion were excluded from my

analysis and are not included in Chapter 5.

In answering questions about empowerment and connections with others resulting in social capital formation, it was essential that mothers were able to tell the story of their decisions about when and how they sought contact with other parents and community members, including the challenges they faced or concerns that arose. Previous research projects in Tajikistan have revealed challenges using survey instruments or questionnaires (UNICEF, 2007). It is difficult to formulate complex questions for translation so that they will be understandable to the respondents, many of whom may have a low level of formal education because of the interruptions in education for their age cohort during the civil war. This was a particular concern in Bokhtar, which is near some of the heaviest fighting of the civil war. It was possible to collect basic demographic information in this way, which I did through a brief questionnaire distributed at the beginning of each interview. Completing this form also helped to orient participants to the research and reassure them that the research was 'real' since many of them conceptualize research as demographic and quantitative.

It was also possible to use focus groups to give association members the opportunity to talk about the services, or lack of them, in their communities. Questions focused specifically on access to education, association membership and the interaction between the two. Sessions were conducted in Russian and lasted an average of 48 minutes. I structured the focus groups based on Stringer's (2014, pp. 111-113) methodological suggestions to ensure that each respondent has sufficient time and emotional safety to express her ideas. This included structuring questions in neutral language and beginning each session with agreed ground rules of mutual respect. The use of focus groups also helped address an unintended consequence of this research project. When parent groups that had not been selected as case studies learned about the research, several approached me and asked to be included. While it was not possible to add additional case studies to the study, I decided to conduct

three additional focus groups to respect their desire to participate and maintain my relationship of trust with these Coalition members.

Table 3.3: Summary of Interviews and Focus Groups

Case Study Research	Interviews	Focus Groups	Case Study Research	Interviews	Focus Groups
Case 1: Dushanbe	**27**	**2**	**Case 3: Bokhtar**	**19**	**1**
IRODA	14		Bokhtar APDC	19	1 (5 people)
SiDa	13	2 (5 + 4 people)			
Case 2: Khujand	**30**	**3**			
Khujand APDC	13	1 (6 people)			
Chkalovsk	10	1 (10 people)			
B. Gafurov	7	1 (7 people)	**Total**	**76**	**6**

Other Interviews and Focus Groups			
Founders / Incubators		OSF Staff	
Sabohat Akhmedova, Rangikamon	21-May	Gulchehra Kabilova, Education Program Officer	30-Apr
Sabohat Hakimzoda, APDC Dushanbe	23-Jun	Zarina Kurbonbekova, Health Program Officer	27-Apr
V. Mirzoeva, NGO Zdovorviye	16-Jun	Zuhra Halimova, Director	28-May
Teacher, Bokhtar (43-167)	15-May	N. Dastambuev, Education Program Director	28-May
Director, Bokhtar (52-120)	14-May	NB: Each interview listed here was conducted in a single session on the date indicated.	
Donors		Other Focus Groups	
Zuloby Mammadashoev, AKF	18-May	Kulob APDC Staff (3 people)	18-Jun
Shohei Kawabata, UNICEF	24-Apr	Kulob parents (8 people)	18-Jun
Johanna Saari, Caritas	10-Jun	Khorog parents (12 people)	6-Jul
Nazira Kurbonova, Mission East	10-Jun	Stakeholder meeting in Bokhtar	1-Jun
Joe Bedarnek, Global Fund for Children	13-Aug	(5 people + town official at the beginning)	

Informed consent

Initial contact with my research participants was straightforward, as I have been working with some of the association leaders since 2008. We were well-known to each other, and a relationship of mutual trust had been established over the intervening years. I contacted the director of each association selected as a case study through email during the proposal stage of this dissertation project to ensure that they wanted to participate and again prior to my arrival in Tajikistan to agree on the timing of site visits and interviews. In both instances, I explained that participation in this research would require individual interviews with approximately 20-25 members of the association, gaining access to internal and public documents, and attending meetings or events to observe the proceedings.

In accordance with Lehigh University's Institutional Review Board policy, I developed an agreement for informed consent that described the rights and considerations of research participants, the way that interview recordings and transcripts would be managed, and whom to contact with any concerns that might arise during or after interviews and focus groups. The informed consent agreement was translated into both Russian and Tajik to ensure that participants understood it fully. In the case of the two research participants who had never participated in formal schooling, another member of the association read the agreement to them in the language of their preference. A copy of the agreement is available in Appendix 6.

I conducted interviews in the offices of the parent associations. Focus groups were conducted either in the association offices, or in an empty classroom in Bokhtar because the association's conference room was in use. All spaces had a door that could be closed for privacy and took place in settings that were familiar to the research participants. Detailed information about the experience of raising a child with a disability was best obtained through open-ended conversation. Therefore, I used

one-to-one, loosely structured interviews with mothers based on the interview protocols provided in Appendix 7.

In the majority of interviews, I worked in Russian with interviewees. If an interviewee spoke only Tajik, I worked with a local research assistant to provide translation.[10] The primary areas of interest to be explored through the interview protocols included the opportunity and motivation for mothers to come together in mutual support groups, experience of advocating for their children within their families and communities, and perceived changes in relationships, self-view and world-view that research participants associate with participation in such groups. With each interview, I continued the conversation until new information was no longer emerging.

This combination of method and setting provided respondents with the maximum possible privacy to tell their stories, which were often emotional. I also used their responses as a guide for further questions and the timing of the interview so that we could build trust for the discussion of difficult topics. For the same reason, I allowed time for more than one session with each of these mothers. Similar to the principle of saturation outlined above for individual interviews, I continued to interview association members at each research site until no new information or topics of discussion emerged (Francis et al., 2010).

Focus groups in each site provided an important opportunity to check and elaborate the themes that emerged from interviews. Bringing research participants together in small groups gave them the opportunity to fill information about the context of the research site, discuss or debate ideas

[10] My local research assistant was a young, newly married woman from Sogdh veloyat who had experience working on iNGO research on parenting practices. She is a native Tajik speaker with fluency in Russian with the sensitivity and experience to gain the trust of research participants when she offered translation. A full terms of reference is provided in Appendix 8.

that emerged from interviews, and offer opinions or information about observed phenomena without having to publicly claim a painful or potentially shaming experience.

Assumptions

Entering this research, based on previous experience in Tajikistan and with these groups as well as others like them, I assumed that membership in such a group is beneficial for the participating mothers. The experience of meeting with others in similar circumstances and facing similar challenges would allow for mutual support and the generation of initiatives to make their lives better. This was the case, and, as expected, mothers reported less stress or feeling of isolation, greater hope for the future for themselves and their children, and improved relationships within their family at the time of research as compared with the time before they participated in the group. However, it was important to check these assumptions by specifically asking research participants about their reasons for joining and staying with the group.

Those mothers who have left the group or have never joined in the first place were impossible to reach during the period of my research. I explored avenues for reaching them, mostly in Dushanbe because of the anonymity that a larger city can afford, although my first priority was protecting the safety of anyone participating in any part of this research. Ultimately, I was able to rely only on the stories reported by members of the group about recruitment efforts that had been unsuccessful or about previous members who had left. These included one family that had participated in the green card lottery, hoping to find more resources for their child with autism in the United States and a mother who had become a teacher in a special boarding school when her child's physical needs became too great for her to cope with alone at home. While interesting, it was not possible to gather enough of these stories to say anything meaningful or generalizable about non-members of the group.

In addition to my assumptions about what mothers might gain from participation, I had some

assumptions about the ways that the groups might change as a result of formal registration and interaction with donor or iNGO-led initiatives. As someone who has worked on such initiatives for many years, I have observed that donor resources can be vital, especially for young organizations, but they can also create a sense of competition that leads to internal conflict and the potential marginalization or exclusion of some members. The ways that funding is offered or the activities allowed within donor initiatives can also shape the activities or focus of civil society organizations, sometime to the extent that they define what they need based on what they believe they could receive from a donor. This has the potential to shift or shape their mission as well as to generate internal conflict over the ways that requests for assistance are formulated or pursued.

Further, I assumed that mothers would prioritize education and health services for their children and that this would figure prominently in their interactions with donors and iNGOs. I guarded against this assumption by rigorously comparing the documentation of donor programs against the needs and plans discussed in interviews and focus groups. I also interrogated it directly through observations and focus groups.

Collecting data: Documentary evidence, member surveys, public events, and observations

"The details of life that the researcher is unable to see for herself are found by interviewing people who did see it or by finding documents recording it" (Stake, 2005, p. 29). Therefore, in addition to interviews with association members, I also made use of interviews with people who worked with the associations, observations of happenings at the associations, public presentations, and documentary evidence available in English, Russian or Tajik to triangulate, substantiate, or elaborate the information provided in interviews. These included photographs from school or family events, videos of association events, artwork completed by the child, correspondence with officials, teachers or other authority figures, or other documents that an interviewee considered relevant to the story. I collected

copies of these as possible and appropriate for development of each case, mostly in digital form so that the originals could stay with participants. As my Tajik language skills are rudimentary, my local research assistant helped with the translation of documents available only in Tajik. I worked with English and Russian-language documents independently.

Table 3.4: Documents consulted

Document type	Title	Status
Web sites	Member pages on the Coalition website at muttako.tj Global Giving page - IRODA	Publicly available
Annual Reports for OSI Tajikistan	2002, 2004, 2007-15	Publicly available (2010-16 online, earlier in the office)
OSI Tajikistan grant reports	Bokhtar association, 2011, 2012 & 2014; IRODA, 2012	Unpublished
Grant report (other donors)	Rangikamon to Caritas, June 2014	Unpublished
Grants to Coalition of parent associations (proposals & reports)	2009, 2010 – 2011, 2012-2013, 2014, 2015, 2016	Unpublished
Trip reports (OSF)	Nov. 2011, Jan. 2012, April 2013, March 2014, Nov. 2015	Unpublished, internal
Organization assessments	IRODA, Rushdii Inklusiia & SiDa – all June 2014	Unpublished, internal
Consultant reports: Jo Baker	Training for new APDC's, May 2012; Central Asia Autism Network report, April 2012	Unpublished, internal
Coalition reports	Meeting report, April 2014 Forum presentations, May 2015	Unpublished

Budget documents	APDC funding table, 2010-13	Unpublished, internal

The documents in the table above provide perspectives on the development of the parent associations from the associations themselves in the grant reports and on their website, from the staff of the Open Society Institute Tajikistan, from consultants engaged by the Open Society Foundations, and from me as I documented my own work with the associations through trip reports. In addition to collecting documentary evidence, I also spent time observing the daily activities of the associations in these three locations. This was important for understanding the types of activities and services that each association has developed for comparison across the cases. It also provided an additional window into the social connections and demeanor of the mothers participating in interviews.

Finally, I conducted a survey of the directors of all 28 associations and 3 initiative groups that existed in 2015 during the period of my field research. A complete tabulation of responses is provided in Appendix 9. The purpose of the survey was to learn more about the structure and sustainability of each of the organizations as well as to find out what types of programs or services they were developing. The former was of great interest to OSI Tajikistan, and so I made copies of the completed surveys available to staff with the permission of the respondents. The latter group of responses was important to my research question about the type of collective actions association members developed.

Table 3.6 provides a map of the research questions linked to each instrument or protocol. Research instruments were translated into Russian. Research instrument 5 (the questionnaire for association directors) was also made available in Tajik if respondents indicated that they preferred not to work in Russian. Shorthand notation is used for each source of information. For example, R1: Q1-6 refers to Research Instrument 1, questions 1 through 6. The title of each research instrument is listed

below. Please see Appendix 7 for the complete set of research instruments noted in the table.

Table 3.5: Sources of information mapped to research questions

R1: Interview protocol, mothers
R2: Focus group protocol, assn. members
R3: Interview protocol, donors – context
R4: Questionnaire for association directors
R5: Questionnaire for mothers
R6: Focus group protocol, association leaders

Research Questions	Instruments
1. Under what circumstances do mothers of children with disabilities in Tajikistan decide to engage in collective action to support their children?	R1: Q1-6 R2 R6
a. How do the connections between the mothers evolve over time in the different geographical and organizational settings of the three cases?	R1: Q4, 5, 7-12 R2: Q3-5
b. From the perspective of mothers of children with disabilities, what type of experiences empower them to take collective action?	R1: Q7-12 R2: Q5-6
2. What types of initiatives, in particular in education, are emerging from the parent groups in the three cases?	Observations Documents R3
a. When and how do they emerge? To what extent are they internally or externally driven and supported?	R2, R3, R4, R6 Documents (reports, project proposals)
b. From the perspective of mothers of children with disabilities, how do these initiatives affect their situation within their extended families and/or communities?	R1 R2 R4
Background information and context	R3, R4, R5, R6

The use of several research instruments and settings provided an important source of triangulation and also informed the process of more in-depth interviews with a smaller subset of the research participants (Maxwell, 2005). Interviewing several women from the same association also allowed for comparisons between them and clarification of questions. Documentary evidence, including from annual reports (2002 - 2014) of the Open Society Foundation in Tajikistan, project proposals and reports, correspondence with schools or other public services, photographs and public notices about events, also provided an important source of triangulation of information provided in interviews as well as a source of follow-up questions for subsequent conversations.

Observing meetings of the associations or activities that they conduct in the normal course of their work allowed for triangulation of interviewee responses to questions about group dynamics and social capital built within the group. Learning who participates in these activities and how often contacts or cooperation with the greater community is demonstrated is a further source of information about the existence and strength of bridging social capital. In cases where these activities are funded through a grant or donor project, interviews with donor representatives and review of project documentation also served as sources to compare information. Finally, the use of focus groups allowed me to ask questions about mutual support, collaboration, and connections in a group setting where the dynamics of the discussion provided important information about the connections within the group to inform exploration of social capital.

Theory to practice: Implementing the Research Design

No matter how well-chosen the methodology, the implementation of a research project always faces challenges and risks that require proactive strategies from the researcher to mitigate. The section that follows discusses the practical and ethical considerations addressed during the study and reviews the

actual implementation of field work to gather data, subsequent management and analysis, and the final compilation of this study.

Ethical considerations

The vast majority of research participants were already known to the author or her colleagues through collaboration with the Open Society Foundations. Thus, there was bond of trust that both facilitated the research and placed an additional responsibility on the researcher. There are important ethical considerations connected to any research project that must be delineated and managed to protect participants (Howe & Moses, 1999). The risks associated with this research were social. Because of the stigma attached to having a child with a disability, the women who participated in my research risked censure within their families and communities. Thus, interview locations and times were carefully agreed in advance with participants to protect their privacy. The names of staff from international organizations and the leaders of parent groups who are easily identifiable, public in their roles and have given permission are identified by their real names. All other names of the participants in this research are coded by their role, such as parent, association member, NGO leader, etc. throughout this dissertation, and each interview subject quoted by name has a pseudonym to ensure that confidentiality is maintained throughout the study unless they have explicitly asked to be identified by their real name. This appropriately mitigates the risk of social censure associated with participation in this research while respecting the right of people to tell their own stories.

In particular consideration of the stigma attached to disability or having a child with a disability in Tajikistan, the author developed the informed consent letter provided in Appendix 6 to assure research participants of the confidentiality of their responses, management of data to protect them, and the ways described above that they would be quoted or cited in any publications resulting from the research. I also explained that no one was obligated to participate in this research or to continue

participation if they wished to stop for any reason. They could decline to respond to questions or end their participation at any time without needing to explain themselves. This appropriately mitigated the risk of social censure associated with participation in this research. The form for informed consent provided also complies with Lehigh University's IRB process.

Discussion including information about children with disabilities in Tajikistan was very sensitive for many of the respondents, particularly when they were asked to recount personal experiences of exclusion within their families or communities and the challenges that their children face. As a result, it was vital to choose research instruments and methods of data collection that provided sufficiently rigorous approaches to triangulation of sources and verification of information received without being overly invasive of participants' privacy or putting participants in uncomfortable situations. If left unaddressed, both of these challenges could have raised ethical concerns about the study as well as resulting in response bias that could have skewed the findings of the research.

It was possible to use focus groups to give association members the opportunity to talk about the services, or lack of them, in their communities. Sessions were conducted in Russian, and questions focused specifically on access to education, association membership and the interaction between the two. I structured the focus groups based on Stringer's (2014, pp. 111-113) methodological suggestions to ensure that each respondent had sufficient time and emotional safety to express her ideas. This included structuring questions in neutral language and beginning each session with agreed ground rules of mutual respect. During focus groups, participants wanted to discuss personal experiences and did so freely because they knew each other well and had shared their stories with each other previously. I allowed these conversations to unfold naturally but was careful not to press any individual in the group for additional details that she might have felt uncomfortable providing so publicly.

More detailed information about the experience of raising a child with a disability was best and most ethically obtained through open-ended conversation. Therefore, I used one-to-one, loosely

structured interviews to learn more about each woman's personal situation, follow up any questions that arose during a focus group (if she had been a participant), and create space for her to decide whether and how much of her story she wanted to share.

This combination of methods provided research participants with the maximum possible privacy to tell their stories, which were often emotional. I used their responses as a guide for further questions and the timing of the interview so that we were able to build trust for the discussion of difficult topics. For the same reason, I also allowed time for more than one session with each of these mothers, in case they indicated a desire to stop and continue later. In the end, no one made use of this offer except for two women who wanted so much to tell their full stories that we ran out of time during the first session and had to make subsequent appointments.

Finally, I faced the unexpected ethical dilemma of being asked to 'name and shame' people, typically medical professionals or government administrators, who participants felt had acted in bad faith or incompetently with negative effects for them and their children. Since it was not possible (or within the scope of this research) to verify specific instances of medical malpractice or corruption, or to interview the doctors or officials to give them a chance to tell their side of the story, I have not identified these people by name. However, I have reported these incidents as the mothers have related them, with shocking similarities across the sample of interviews, and have no reason to doubt that they are faithfully relating what they have experienced.

Data collection and analysis

The Open Society Foundations generously provided a 16-week sabbatical to undertake the fieldwork for this dissertation between mid-April and mid-August 2015. IRB permission for the study was sought in the first quarter of 2015 and defense of the proposal for this dissertation was completed in March 2015. (Please see Appendix 5 for the completed IRB application.) The fieldwork required a

minimum of two weeks in each of three sites for a total of six weeks. In addition, I spent an additional week in Dushanbe to make preliminary arrangements to visit sites and another week to gather information from donor agencies and iNGOs for a total of eight weeks in-country. During my field work, the President of the Open Society Foundations visited Tajikistan, so I returned to work for approximately one week. He accompanied me to my research site in Bokhtar and held a meeting with local government representatives and stakeholders, providing an additional and unexpected research opportunity.

Finally, I took a few days for personal travel, three weeks to contact the associations participating in the research with follow-up questions and to organize and conduct additional focus groups in Kulob and Khorog, and a short series of home visits in Murghab undertaken because these associations expressed interest in participating in this research and indicated that they might be offended if they could not. As mentioned above, in the interests of maintaining a good relationship with the whole network, I decided to conduct focus groups wherever I was asked. In Murghab, the director of the association decided that home visits would be more appropriate than a focus group as well as accommodating those mothers who would have had difficulty arranging childcare to attend an event outside their home. In total, I spent roughly 13 weeks total in Tajikistan between April 26 - July 14, 2015.

Although at the research proposal stage we planned approximately 10 interviews per site, through the course of the field research, the additional interviews were necessary to reach the saturation point where no new themes or ideas were emerging from discussions. In addition to the large themes emerging from the site as a whole, I also wanted to be sure that I was reaching saturation of themes from the smaller sub-groups of participants, such as parents of children with autism spectrum disorders vs. Down Syndrome in Dushanbe or parents from different parts of Soghd

veloyat. I was careful to interrogate my assumptions throughout by triangulating data through the use of multiple sources, which include observations, documents, interviews, and member checks. Furthermore, continuing to refine and repeat interview questions throughout the data collection helped me to reach a point of saturation over the three cases such that no new or surprising information was coming to light at the end of the process of field research. As a result, the total number of interviews is larger than initially planned.

Data management and coding

This research generated a large amount of qualitative data to be managed and analyzed, including two 2.5-inch binders of interview and focus group transcripts. In order to ensure that data was managed well, I developed a system of cataloguing data by research event, date, and location across the three cases so that it could be easily accessed by searching a dedicated folder stored on Dropbox. Due to the IT security threats that face the Open Society Foundations, I have ensured that my Dropbox account is attached only to my personal email address. I also used the maximum security settings provided and changed my password regularly in order to ensure the security of the transcripts, recordings, and other information used in this study.

Recognizing that "issue development continues from beginning to end [and so] some write-up begins after the first contact with people" (Stake, 2005, p. 30), throughout the period of field work, I wrote frequent in-process memos, sometimes as often as twice a week, to capture evolving questions for further exploration, gaps in my understanding, and commonalities among research participants and sites. This research method is suggested by Stake (2006) but also has a firm basis in the ethnographic approach.

> Ethnographic fieldworks characteristically seek to collect and analyze data simultaneously, allowing analytic concerns generated by initial observations [interviews, and focus groups] to

> guide and focus the collection of new data. Developing potential analyses requires writing: The ethnographer turns from mentally noting theoretical insights and connections to putting these ideas into written form. When insights are simply thought or communicated orally, rather than being put on paper, they remain loose and fluid…Written-down analyses acquire structure, depth, and nuance. (Emerson, Fretz & Shaw, 2011, p.123)

As themes began to develop through the process of writing in-process memos, I developed tags as an evolving series of key words that later supported the development of codes. Recognizing that these tags formed the beginning of an indexing system and thus are not analytically neutral (Mason, 1996, p. 108), I checked them against my own assumptions and the evolution of the research on a weekly basis. As agreed during our discussion of the dissertation proposal, I undertook a literal reading of approximately 30% of the material generated for each case before developing a final draft of the codes to be used in analysis of the whole data set gathered during field research. I then used colored highlighters and the margins of interview and focus group transcripts to apply these codes across chunks of data from each case study.

For example, I highlighted in pink any reference to reasons for joining or seeking out an association throughout the interview transcripts. As I developed the codes by re-reading field notes, transcripts from research events, and in-process memos, I began to write short memos to describe the characteristics of each code and to mark quotations from transcripts that exemplified these descriptions in a particularly clear or vivid way (Emerson, Fretz & Shaw, 2011, pp. 185-88). Following this process, I returned to the color-marked transcripts and wrote an abbreviated code description in the margin based on the characteristics matched by the given section of the transcript. This, in turn, supported the entry of responses into a master spreadsheet using a numerical value for each coded response. See Appendices 4 and 10 for the complete master spreadsheet and list of codes.

Although each case in a multi-case analysis is developed in its own right as the narrative of a

discrete phenomenon, the logic in choosing this method was to explore commonalities among them in order to say something about their intersections as more generalizable lines of inquiry that explain a larger phenomenon in a specific context (Stake, 2005). Specifically, I was examining "different activity in different settings, looking for 'correspondence' [or] patterns of co-variation" (Stake, 2005, p. 28). Therefore, I analyzed data by developing a coding system that first identified large themes that connected across cases and then broke these into smaller themes more specific to individual cases. Reading the complete transcripts of interviews and focus groups when the research was one third complete, at the end of the field research period, and again in the development of each case has provided sufficient familiarity with the dataset for me to pull out these themes and code them accurately, again checked by my research assistant.

In order to make this manageable without physically cutting and pasting large amounts of paper, I then used electronic tagging for codes or groups of codes to better manage files. I developed focused codes (Emerson, Fretz, & Shaw, 2011, p. 172) myself and coded data independently to safeguard participants' confidentiality. To facilitate this, I printed the transcripts from interviews and focus groups, organized them in binders by research site and highlighted the emerging themes in different colors. This provided a good visual representation of the themes and allowed me to catalogue them in a spreadsheet with the demographic information from each research participant. The complete Master List of Interviews is included in Appendix 4.

Once this was complete, I thought about asking fellow PhD candidate to review this process and the resulting codes so that they could be finalized and applied across the whole data set. Working with a fellow researcher who is unfamiliar with the dataset would have helped to identify any discrepant data or irregularities in the coding when compared to the theoretical framework resulting from incorrectly entered data, inconsistent coding, or other human error.

However, a great deal of the material collected, including transcripts from interviews, was only available in Russian. The only fellow student in my program who has the necessary language capabilities was already in the Russian Federation working on her own field research at the time when my data was ready for this check. Since the Open Society Foundations was declared an 'undesirable organization' by the State Duma of the Russian Federation in November 2015 and the subject of my research is closely entwined with the work of OSF in Tajikistan, I could not in good conscience send copies of raw data on such a sensitive topic into Russia so that a fellow student could check my coding. Instead, I double-entered all the data myself and asked my research assistant check the resulting dataset against the original questionnaires and interview transcripts. This has ensured the accuracy of recording and data entry.

Forming the cases: Analyzing themes

Some of these themes emerged from research participants own identification and were nearly universal, such as the importance of finding other people with a similar struggle. It was important to use this as a starting point because it forced me to think about pre-conceived ideas that I might inadvertently have brought to the research and further give voice to participants. My task as a researcher was "not simply to identify member-recognized terms and categories but also to specify the conditions under which people actually invoke and apply such terms in interaction with others" (Emerson, Fretz, & Shaw, 2011, p. 167), thus "providing the opportunity for participants to understand their own experiences in terms that make sense to them" (Stringer, 2014, p. 137) and can be shared with the wider community and world for increased understanding of empowerment and collective action for mothers of children with disabilities. Thus, I took the grounded theory approach that Emerson, Fretz, and Shaw (2011) recommend and used respondent suggestions as a starting point to develop themes and sub-themes, with attendant codes, and then checked with respondents toward

the end of the field research to find out if they saw any misunderstanding or inaccuracy.

This process meant that I developed detailed notes during each research session, including interviews, focus groups, and observations. At the end of each day, I made sure that they were transcribed or captured electronically on a secure hard drive and uploaded to Dropbox as soon as internet connection permitted for future use. At the end of each week, I re-read my notes to make in-process memos (Emerson, Fretz, & Shaw, 2011) about themes, expressed through repeated phrases or stories, that seem to be emerging. I then used subsequent research sessions to check this analysis.

At the end of my field research I maintained contact with research participants by Skype and subsequent visits to Tajikistan in November, 2015 and January, 2016 to member check themes as they became more solidified for data coding. "The qualitative paradigm assumes that reality is socially constructed and it is what participants perceive it to be. This lens suggests the importance of checking how accurately participants' realities have been represented in the final account" (Creswell & Miller, 2000). This was an important choice for this study because the views of the research participants are central to the validity of the study's empowerment framework which necessarily situates this study within a critical paradigm (Christens, Inzeo & Faust, 2014). In using member checks, I also hoped to minimize any feelings of inequality between myself and the research participants (Creswell & Miller, 2000). In selecting the research participants to engage in member checking, I focused on the founding or most active members of the associations as the people who would have the broadest experience and the greatest relationship of trust with me. I also made sure to keep to themes and otherwise anonymized information so that I would not compromise the confidentiality promised in the informed consent (Krefting, 1991).

I began identifying themes by re-reading all of my notes to ensure that I was not unduly influenced by later interviews and focus groups. The final list of themes and codes are provided in Table 3.7 below.

Table 3.6: Themes, sub-themes and codes

Method of joining the association	JOIN	Negative family reactions	NEG
founding member	1	Mother- or Father-in-law	1
word-of-mouth or referral	2	Husband	2
outreach from the association	3	Extended family	3
sought after event or media information	4		
When learned of disability	**TIME**	**Experiences in healthcare**	**MED**
At birth	1	Offered institutionalization	1
Infancy	2	Offered euthanasia	2
Toddler or older child	3	Disability defined in hopeless terms	3
Acquired disability	4	Difficulty identifying disability	4
		Given misinformation	5
		Unkind or discriminatory behavior of healthcare workers	6
Family support	**FAM**	**Benefits of assn. membership**	**BEN**
Own mother	1	Shared experience - mutual understanding	1
Husband	2	Information sharing	2
Sibling	3	Improved access to expertise	3
Other	4	Provision of services	4
		Material support (job, money, childcare)	5

Finally, as I developed the case studies, I discussed preliminary results with a colleague at OSI Budapest with experience working in Central Asia with grassroots community groups. This proved helpful in ensuring that the development and findings of each case were clearly communicated. My colleague's experience in the region working with similar groups meant that she was also able to spot

places where I may have been relying on assumptions or conventional wisdom, sending me back to my dataset to confirm the evidence for my findings. This approach was more useful than the support that a fellow doctoral student unfamiliar with the geographical context of my research could have provided. It also had the distinct advantage of not requiring the translation of research materials, as my colleague is a native Russian speaker, and conforming with Open Society Foundations' security protocols and the ethical intentions of the IRB process.

Limitations of the study

> Even when the study is well done, the research questions will not be fully answered. Some assertions can be made that partially answer the question, but ways the questions need to be improved will become apparent. So the case study report is a summary of what has been done to try to get answers, what assertions can be made with confidence, and what more needs to be studied. This seems like 'slim pickings,' but the quality of the investigation, the increased familiarity with the program and the phenomena, and the new realizations of complexity can make the research community proud. (Stake, 2005, p. 14)

Stake suggests that cases should be chosen based on three criteria: relevance to the quintain, capability of showing diversity across contexts, and provision of opportunities to learn about complexity and contexts (Stake, 2005, p. 23). The cases summarized above provide a robust overview of the parent associations across Tajikistan with two significant limitations. First, there is no case study for the Gorno-Badakhshan Autonomous District (GBAO). This region is culturally and religiously distinct from the rest of Tajikistan. The majority of the population are Ismailis and the languages spoken here are substantially different than modern Tajik. Conducting research in GBAO requires additional government permission because of the regions greater autonomy. It is also physically difficult to access, requiring a 15-hour Jeep ride or a flight known throughout Central Asia for its difficulty and propensity for last-minute cancellations. The time available for this research did not allow me to develop a case in this region. This would be an area for further research to complement the cases here.

The second limitation of the study is the lack of exploration of the relationships between the association in Bokhtar and the associations in the surrounding area. The dynamics of relationships among associations are readily apparent in the Dushanbe and Khujand cases and offer rich material for comparison. During my research in Bokhtar, it was clear that there was a relationship with the association in Vakhsh and also in Kulob, but there was not sufficient time for me to explore this deeply. Further data collection focused on surfacing these relationships to add to the richness of the Bokhtar case provide material for cross-case comparison.

Chapter 4 : Common Cause, Different Paths

Setting the stage

These three case studies tell the stories of parent associations in three different parts of Tajikistan. All the organizations profiled here seek to empower parents of children with disabilities to support their children. There is a national Coalition of Parent Associations that brings together 31 such groups nationally. The goal of the Coalition is to amplify the voices of the members to advocate for better policies affecting children with disabilities and their families, push for funding and implementation of existing mandates, and share expertise built over years of navigating the upbringing of children with diverse challenges. When I began this research, I planned to profile only three associations within this Coalition. Working with two groups focused on disability generally, one in an urban center and the other in a small town, complemented by a third group in the capital focused on a single disability, would give a picture of the diversity of settings and foci of parent association across Tajikistan. Cases focused on three associations, all members of the Coalition, would also provide a large enough sample to be able to say something meaningful about empowerment spiral developed in Chapter 2 in response to my research questions.

The choice of the three associations would also capture a differing understanding of disability and inclusion within the Coalition. The Dushanbe APDC led by Sabohat Hakimzoda and many of the regional associations that they originally supported, including the group in Bokhtar profiled in this chapter, focus on the rights of parents under current legislation. They advocate for the existing system of assessment of disability, provision of pensions, free medical care, and special schools to function competently and transparently. The other three organizations in Dushanbe and members of the Coalition in Khujand and Khorog would like to see substantial changes to the existing system that

reflect the social model of disability, which includes inclusive education and changes to medical guidelines and processes for assessing disability.

As my research evolved through interviews and focus groups, it became clear that shifting focus from a single organization alone in each place to writing about an organization, almost as a protagonist within a larger cast of characters, (i.e. within the networks and connections in each place) would yield richer case studies that would be better matched in explanatory power to the sample of interviews and focus groups. In this sense, each case study becomes a story with a parent association at the center and a cast of supporting characters rather than a profile of a single organization.

For example, in Khujand, the parent association harmoniously shares the stage with the NGO *Rangikamon*, which incubated them, as well as with the newer associations in the outlying districts of Soghd veloyat that they have incubated in turn. It serves as a case study about ways that an empowering organization might beget an empowering network. In Bokhtar, the parent association remains joined in a tight sisterhood to the rural development-focused NGO that first received funding to gather parents. This case is particularly interesting for the way that international assistance interacts with local needs and collective action to provide a complex organizational arrangement with a mission for every donor.

In Dushanbe, where parent associations have been active the longest, the size of the population makes space for diverse associations. There are four groups that grew from the original project at the NGO *Zdoroviye* to empower parents. The central character in this story, IRODA, focuses on autism spectrum disorders. It provides an interesting case of organizational development over time in a field that sometimes feels crowded. Working with IRODA helps frame the question of what it means to be an empowering organization in an environment that remains disempowering. The most important supporting character in this case is SiDa, the association of parents of children with Down

Syndrome. A much newer association, SiDa helps triangulate IRODA's story of organizational development. The differences between the ways that parents learn of their children's autism or Down Syndrome paired with the similarity in heightened discrimination against people with intellectual disabilities also offer important points of divergence and convergence.

Finally, the NGO *Zdoroviye* and the Dushanbe-based Association of Parents of Disabled Children directed by Sabohat Hakimzoda appear in flashbacks within the cases set in Bokhtar and Dushanbe, highlighting the revolutionary shift in thinking about disability needed to establish parent groups with a public mission as well as the competition and discord that can occur when the founding members of any movement disagree about the best way forward in an environment where resources are scarce.[11]

Empowered mothers, empowering organizations

As I conducted field research, it became clear that the mothers in each case study and the associations that they have formed are at different places on the empowerment spiral. The associations are also at very different stages of organizational development, although all show at least three of the characteristics of empowering organizations that Maton and Salem (1995) describe:

> The organizational features found to characterize all three settings were (a) a belief system that inspires growth, is strengths-based, and is focused beyond the self; (b) an opportunity role structure that is pervasive, highly accessible, and multifunctional; (c) a support system that is

[11] The fourth organization that grew from the NGO *Zdoroviye*'s work is Rushdii Inklusiya. The founding director of this organization is the parent of a child with disabilities, but Rushdii functions as an NGO focused on improving the quality of education. Although still connected with the parent groups and active in policy advocacy, Rushdii does not appear in these case studies. For more information about this organization see: Lapham, K. (2016). Including Children with Disabilities in Tajikistan's Education System: Global Ideas, Local Tensions. In I. Silova & S. Niyozov, *Globalization on the margins: Education and post-socialist transformations in Central Asia* (2nd edition). Charlotte, NC: Information Age Publishing.

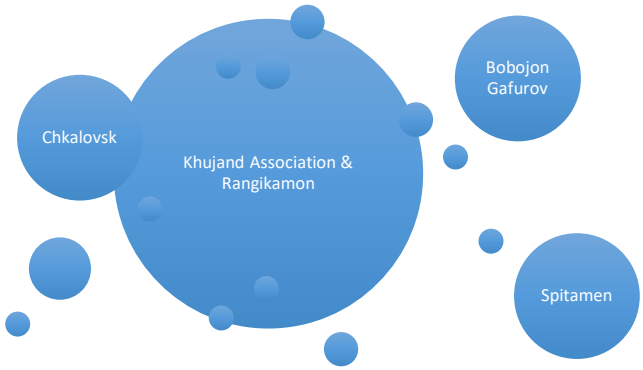
> encompassing, peer-based, and provides a sense of community; and (d) leadership that is inspiring, talented, shared, and committed to both setting and members (p. 631).

When superimposed on the empowerment spiral, each of these characteristics bears some relationship to the elements of individual empowerment translated into supportive conditions in an organizational setting:

a) The belief system described by Maton and Salem (1995) could contribute to the pursuit of knowledge, a sense of self-efficacy, and critical awareness if focused on political or social context.
b) An open opportunity structure within an organization would contribute to collective action by keeping the conversation open to suggestions and initiatives from any member as well as strengthening bonding social capital by making connections within the group accessible.
c) The support system described is the essence of bonding social capital.
d) The type of leadership described could set the empowerment spiral in motion for newcomers and could also lead to the development of bridging social capital if initiatives become outward facing.

These, in turn, respond to elements of the research questions, aiding the exploration of the types of experience that lead to greater empowerment, the space for collective action or interrogating who drives choices within the parent associations, the evolution of the connections among mothers over time, and the types of interaction they experience with the greater community. Thus, Maton and Salem (1995) offer some useful signposts for suggesting where the membership of each association might sit on the empowerment spiral as well as some clues about the future trajectories of each organization. We now turn to the three individual case studies but return to this analysis through the comparisons in Chapter 5.

Khujand: Expanding a network of empowering organizations



Khujand is the second largest city in Tajikistan and the administrative center of Soghd veloyat. Called Leninabad in Soviet times, Khujand is one of the oldest cities in Central Asia with documented history dating back more than two and a half millennia. It is located in the rich Fergana Valley, which was purposefully divided among Kyrgyzstan, Uzbekistan, and Tajikistan following the Bolshevik conquest of Central Asia so that no one Soviet Republic would have control of its agriculture and water rights. Relatively untouched by the civil war of the 1990's, Khujand was nonetheless adversely affected by independence. The advent of an international border between Tajikistan and Uzbekistan cut residents of Khujand off from the cities of Samarkand and Bukhara, their closest large neighbors. Similarly, the city was cut off from Uzbekistan's power grid and separated from the rest of Tajikistan by mountains resulting in shortages of electricity that continue to plague the city in the winter months.

The parent association in Khujand, called the Association of Parents with Children with Problems in Development, has been located in a shared office space with three other NGOs – once a private home built in dark marble by a wealthy local businessman as a family compound - since July 2014. It is located near the main university campus and the provincial police station, so it is easily accessible by public transportation from the center of town about 10 minutes away and from surrounding districts between 20 and 60 minutes away. The association was incubated in a health-focused NGO, Rangikamon, similar to the associations in Dushanbe. In fact, Rangikamon has an

office in the same building as the association. However, unlike the organizations in Dushanbe, the relationship between the incubating NGO and the parent association remains close and collaborative.

Beginnings: Founding the association in Khujand

In the early 2000's the NGO Rangikamon had funds from UNICEF and was working with the local PMPC to offer 'rehabilitation' services for children with disabilities. The director of Rangikamon began working with parents specifically in 2008 with funding from the Open Society Institute Tajikistan. At the same time, Operation Mercy was funding an early intervention program at Kindergarten 26 for children with disabilities where many of the founding members of the association were also taking their children (23-39-148). Cross-membership in these two groups makes it hard to say where the founding mothers first met and connected. The director of the NGO, Sabohat Akimovna Akhmedova, herself a mother who had lost a child, identified Nazira Muminova as an active mother and capable worker after meeting her during Rangikamon's activities for children. She hired Nazira to conduct research on the challenges facing families affected by disability. Sabohat Akimovna recalls:

> In 2008 we started studying the problems of parents with children with disabilities. At that time Nazira was already visiting our center to get services with her child. Among parents she was different - she was very communicative, professional, and very creative. We asked her to do a survey for us with several families since they trusted her. Everything started from that. After that, she surveyed about 30 families in Khujand and made a great report. She wrote about the problems and opinions of parents very concretely. (37-03-117)

Nazira went house-to-house, even speaking with those families who had put their children in institutions. The problems that these families frequently mentioned included financial difficulties, lack of knowledge about or access to services, and feeling isolated. This research became the springboard for the formation of a more formal association. Nazira had built trust within the community of

mothers, indicating an evolution of connection from shared experience to trust and leadership. Nazira also was beginning to gain confidence in herself as a leader.

In 2009, OSI Tajikistan announced an open call for proposals to support the formation of parent associations. With support from Rangikamon, which had already been a partner for OSI Tajikistan, Nazira decided to work with two other mothers to set up a parent association separate from Rangikamon. She and her colleagues were able to develop a proposal that generated the initial funding to set up the association and register it. This was a huge learning experience for Nazira. She explains:

> The project started in August 2009 but it took time to register. We had some problems so it took us time to register fully as an organization. At that moment when we started working, we had no office space, no resources. We didn't have anything. It was very difficult. We were inexperienced. I didn't know how anything worked. I got some experience when we had the project from Soros [OSF] because we held seminars for parents within that project. … Our first project as an organization was about the rights of children and teaching parents computer skills. We did this because we felt that improving the lives of parents, to help them find employment, they needed these skills. So we organized a course for 16 parents and 2 children – they learned basic computer skills. (54-15-181)

This mixture of training programs is important to the members of the association and unique across the three case studies. All of the associations in the Coalition offer seminars on the rights of children and the ways that the social protection system should support children with disabilities under current law. However, the association in Khujand is also seeking to address the employment and job skills needs of mothers who may be on their own, either as the result of having a child with a disability or a husband's labor migration. Such training is a different path to solidarity and social capital than meeting through a program for their children, but it is no less powerful. For the association, providing job skills workshops means that they need to maintain strong connections to the rest of the community and maintain a relationship with Rangikamon that supports fundraising. For the mothers, having

marketable skills could raise their status within their families and the community, providing an important path to renewed social connections and empowerment.

Building a network: Reaching out to others

Since that time, the confidence among Nazira and her staff, as well as the trust within the community, has grown significantly as they have learned how to navigate the challenges of running an NGO in Tajikistan together. They have reached out to others, including the parent association in Isfara which was registered around the same time as the Khujand organization but is located in a significantly more remote town and put many of its activities on hold when the director took maternity leave. The Khujand association has also incubated smaller associations in district centers and has taken a turn as coordinator for the national Coalition of Parent Associations in 2015. They have implemented difficult projects on their own, like an initiative with Handicap International where they had to convince the city administration to make a local clinic more accessible. According to Nazira,

> First, we did some monitoring to find out how many people with disabilities use each clinic and based on the results, we chose a clinic to build a ramp. When ramps are built here, they often do not conform to international standards. They are too steep. It was a long process for Handicap to approve the structure and plans – it took a long time. It was also difficult because we were supposed to agree with the city administration to do this for free. We had to convince them to give us an architect, construction company, etc. Our construction companies are private, so they might not agree to do this [for free]. It was a long process but now it is there and people use it. They thank us for doing this. It is one of the examples for other clinics to also become more accessible. (54-15-181)

A focus on the needs of parents and a strong desire to be relevant still characterizes the association. Rather than separating these functions under different legal umbrellas, as the association does in Bokhtar, the Khujand association keeps them within a single organization. This could be related to the differences in economic development and funding opportunities between the two regions. Soghd is much wealthier than Khatlon and is also thought to be one of the better educated and more

progressive regions of the country. Several donors, including UNICEF, Ablis, Operation Mercy, and Handicap International, identify Khujand as a target area for funding.

This means that the available funds for projects related specifically to the needs of children with disabilities and their families may be enough to sustain the organization without having to 'sell' their work as rural development, women's programs, etc. as some of the associations in Khatlon must do. It also could be easier for the association in Khujand to make a case for projects not directly related to disability or childcare as part of their mission, like the computer skills classes, particularly as this is characterized as having direct demand from parents.

In addition, the computer literacy classes, which still continue sporadically, were taught by a mother who had worked in IT before having a Deaf child and joining the association as a staff member, adding a component of mutual parental support. Led by a mother and association member without fundraising, these classes demonstrate the openness of opportunity structure in the Khujand association and could be viewed as a form of collective action among the participants and instructor. Additionally, there is an evolution of connection from a shared experience in the classroom to social capital as mothers bond with each other over the shared experience of trying to make ends meet while raising a child with a disability.

This orientation toward mutual support and learning from each other could also be related to the association's rejection of the charity model of disability, which portrays people with disabilities as objects of charity incapable of asserting agency (Katsui, 2005). Nazira gives an eloquent account of the association's initial flirtation with the possibility of charity from private donors and humanitarian assistance:

> When we started our activities, people found out about us and did come to us to ask how they would help these children. We said that some families need Pampers or food, and we collected

> these things to distribute to families. We noticed that the [receiving] families got used to this and started to depend on humanitarian assistance. We told them that this would be only a one-time possibility, that we would only distribute things when we had them. Even people who are relatively well-off, they would try to get something. Even though they were not in need, they would try. We tried to assess which families would go completely without and help them. But we have always tried to stay away from the charity model. It is not for us. We try to say that our objective – today you have this help and you will be full, but what happens tomorrow and the day after? When your child is an adult, he cannot depend on humanitarian assistance his whole life or on that miserable pension that isn't enough for anything. Please think about that. Let's [work together to] help your child develop his talents – look at what he can do. Maybe he is not going to finish his education or become a professor. That's not important. It's important that he finds a place in life based on what he can do. (54-15-181)

While recognizing that some families are in crisis and need material support, the association in Khujand clearly is reluctant to engage in this type of work. They would rather focus on activities that support families to help themselves and their children. Even in trying to provide direct assistance, they focus on the long term. For example, they have hired a mother in dire straits as a cleaner for the office so that she could have a flexible work environment and earn something to support her family (Farangis). There are other organizations that provide humanitarian assistance or charity, so they will make referrals but no longer accept humanitarian donations to distribute. This is a contrast to some other organizations in this study, in particular the association in Bohktar and SiDa in Dushanbe, which both provide humanitarian and material support to the greatest extent that they can.

In line with this orientation toward helping parents plan for the future, the staff of the association have noted increased confidence and feelings of self-efficacy among the parents working with them. In Nazira's words:

> They are self-confident. They were not before. They would ask, how can I go to school and ask them to teach my child? They had no confidence in themselves or their children. Now they have much greater confidence. They say, my child is like this but he can learn. I will help him. I will sit with him in class if necessary but most important - he is going to study. (54-15-181)

This is an important shift in several ways. First, it requires overcoming ideas about disability as a static condition that makes it inherently impossible for a child to learn or change. Seeing changes in their children from working with them through the support from the association's workshops and expert advice, beginning with Rangikamon and extending to increased expertise centered in the association, helps parents see their children as capable of studying and learning to the extent that they are willing to overcome the physical hardship and expense of sending a child to school. These include inaccessible transportation, which becomes more difficult to navigate in winter, formal or informal fees (15 to 150 TJS monthly) for various types of schools, the cost of school clothes and supplies, and chronic electricity shortages in the winter that make schools cold and complicate even the most basic household tasks in a city of apartment-dwellers.

All of the barriers to education in mainstream schools for children with disabilities underline the determination of this mother. The idea that she can attend classes with her child and provide effective support indicates a sense of self-efficacy. What she can do will make a difference for her child, and she has enough confidence in the skills that she has learned to try. In the association, she also has a place to turn for help and advice if she runs into problems. Finally, she has also been able to negotiate a significant investment of time with her family, indicating a level of support from them.

Bridging social capital: Extreme discrimination and returning to society

For many families, educating a child with a disability represents a significant investment of time and money in their child, which may or may not be supported by the people responsible for making decisions in the family. In this sense, the decision to send a child with disabilities to school can also be an ongoing diplomatic negotiation within the family as well as with school personnel. However, an important part of the association's success is the ability of the association's staff and founding members to support and build trust among families with the ultimate goal of overcoming

the social stigma and difficulties that come with having a child with disabilities in Tajikistan. Nazira reinforces this point:

> In the future, we [the association members] hope that they [other mothers] will not feel discrimination and alienation, that parents who give birth to these children will not be depressed. That they [children] will be able to get education without barriers. We want them to pass calmly through these doors, not have to knock them down and prove that their children can study in school. I experienced this myself. My child is now in 4th grade. He has cerebral palsy and does not walk by himself. When we went to the PMPC to go to 1st grade, they asked me if I was sure that my child could go to school. We know that you can enroll him there but are you sure that the other children will accept him, that it won't be too stressful for him? The people in the Commission, doctors, they suggested that maybe I should not enroll my son in school but should sign him up for home-schooling instead. I said, ok, look at this situation where a child sits at home for 18 years, doesn't go anywhere. When he needs to go somewhere independently – the pharmacy or the store to buy something – how will he be able to do that? How will he go outside, get on the bus and go somewhere?
>
> I won't be with him for his whole life. If he goes to school, it will be his first step toward independence. It will be the first step for him to be able to take care of himself. He needs to have contact with children his own age and develop together with them. It will be his first step to have this contact. Maybe he will have some delays, but this will help him develop. I was not wrong about this. I tell other parents to take their children to school every day even though it is hard, despite the cold in the winter, so that they will have contact with other children and not sit at home for days at a time. We won't be with them always. They will have to go out into society and live independently. (54-15-181)

This is not by any means an easy path. To whit, the association leaders first mention the need to work with grandmothers in 2011. Although respondents reported negative reactions from their mothers-in-law in all three research sites, the most extreme accounts of discrimination within families came from Khujand. This problem may be particularly acute in Soghd. It is the only region where parents spoke openly in both interviews and focus groups about suggestions from healthcare workers (and in one case a mother-in-law) that a child born with disabilities be euthanized, making the idea of institutionalization seem commonplace and benign. This suggestion was recounted in the context of a shocked reaction from parents who have refused to go along with it, as told by this focus group participant:

> Right after my child was born, the doctor said that he would be different from other children and suggested to my husband that we give him a shot. My husband thought that the shot would make him better but the doctor said, no, our child was beyond hope and would not become better. They would give him the shot so that he would go permanently to sleep. My husband was horrified and responded that our son should live as long as fate allowed and that he would care for him. (Focus Group participant: 23-39-148)

Views that the doctors offering this meant well or did not know any better were also expressed in the focus groups and subsequent interviews, indicating an accepted and deeply negative attitude toward disability in society. Fears of bullying by classmates and the inability of teachers to work effectively with their children are pervasive for both parents whose children become disabled through illness or accident and those who have a congenital disability. In this context, the desire to send a child with disabilities to school indicates that the parent and the family have come to terms with the public aspect of having a child with a disability in Tajikistan. Making peace with the public perception of disability does not mean accepting it. One of the association members recounts:

> Before, I didn't want to show my child to anyone. When you go out into the street, everyone points. It made me feel bad that everyone was laughing at my child. You can't do that, but not everyone understands that yet. (9-35-194)

In discussing the ways that this should change, several parents indicate the beginnings of critical awareness. Together with their connections to each other, this sense of injustice opens the door to collective action.

There has been progress in education policy in the recent past that supports the development of inclusive education, including the National Concept for Inclusive Education in 2011, developed in part by members of the Dushanbe parent associations serving on a government-convened working group, and presidential support for people with disabilities in a televised speech in spring 2015. However, it has also proven difficult to negotiate relationships with schools to accommodate children with different types of disabilities, in particular children with autism or intellectual disabilities,

indicating the need to work together and support each other. One interview with a mother in Khujand illustrates this tension between the idea and current practice of inclusion clearly:

> Doctors have told us that we should send our children to a regular school, instead of a special school, so that they become used to normal life. Since our President has made a statement about this, people have begun to understand this a little. But in school, my son couldn't go to the toilet by himself and he could not wait. The teacher [did not help him and] sent him into the street to go home in that [dirty and wet] condition. (49-06-187)

This mother's desire for her son to experience and navigate the abled world by going to school with his peers confronts the harsh reality of the conditions in many schools and the attitudes of adults, including teachers, which have not evolved past the traditional stigma of disability. The result of this shaming incident was a search for a different placement with a more sympathetic teacher.

Empowerment and respect: Outpacing the professionals

An orientation toward education for their children regardless of the barriers, has led some parents from the initial group of mothers who met at Kindergarten 26 to grow considerably as specialists in different fields. For example, in 2013, Nazira herself studied in India on a 3-month course on inclusive education. Founding members of two other Coalition member associations have also studied in this program, which required a personal contribution of 15% of costs from Nazira and a commitment to implement a project and report on it before receiving a certificate. The credential provides legitimacy for knowledge gained from her own experiences, while the course requirements gave Nazira a way to structure training programs for others.

Another mother has learned a very great deal about children with autism from a combination of self-study and contact with the association IRODA in Dushanbe. She now makes home visits to other families on behalf of the association and Rangikamon. Clearly, well-educated to begin with, she has applied her intellect to learning about strategies for supporting children with ASD and notes that

some specialists have been surprised that she is not a doctor herself. Responding to a question about how professionals relate to knowledgeable parents, she explained:

> When we went to Moscow, I prepared myself. I read a lot and when we talked to the neurologist she asked if I had a medical education. I said no – I had just read a great deal and was expressing myself in medical terms. I studied a great deal and read about autism. (59-34-107)

Her experience highlights the expectation among many professionals that parents will not be knowledgeable or well-informed about their children's disability. Although highly educated and working as a university professor in political science, the connection to IRODA was essential for her to sift through the information available on the internet and through self-study so that she could feel confident in her knowledge and make sense of what she wanted to do. The same mother also provides the home visiting service that Rangikamon and the association have started with project funding. She speaks about her training and work with pride and professionalism:

> Before the association had opened, [the director of IRODA] came to Kindergarten 26 and said that she had the idea to open a specialized center for children with autism. Last year I also attended a seminar in Dushanbe. I know them and I have also used their methods with my son. At first I worked on the Teach program. I got it from the internet and worked on it with a speech therapist and psychologist. I have also used the program on applied behavior analysis at home with [my son].
>
> We were trained, several of us, on the Portage program and two of us parents were chosen, including me. Work on Portage means that we use their guidelines and we make home visits. First, there is a consultation and assessment here [at the center] and the specialists give us a plan for developing skills in children. We identify the priority problem and work in that direction. I visit each of six families once a week for about two hours. Each child has his own portfolio where we track and assess his development, keep track of his individual development plan. We work based on this plan and step by step help children master new skills. When I first visit a family, I observe them – what kind of family, what do they want for the child, what to they want the child to be able to do. Then we set concrete goals together based on what the family wants and what the child can do.
>
> There are many families who want [these services]. The specialists [at Rangikamon] choose the families. The main principle is that we visit children who are difficult for their families to

> bring to the center. For example, if they cannot come to the center once or twice a week, then we do home visits. Sometimes we also visit very hyperactive children at home because it is difficult to work with them at the center. They do better in the home environment.
>
> [Before I had Portage training] I studied international economics. In working with defectologists, speech therapists, working with my own son, they saw and invited me. I went to a seminar on early intervention in Dushanbe and also one on autism. And then I went to Portage and they chose me. [Laughter] You could say that [I have become an expert]. It's a new field. I am surprised myself. I taught in university before. Since I graduated with distinction (*красный диплом*) the university kept me on for two years and I taught. Then I was pregnant with my second child and also had to focus on my older son [with autism]. (59-34-107)

Already well-educated and supported by her husband, this mother has focused on increasing her knowledge about the disabilities that affect her children. She has developed the skills to support them to such an extent that she has become more qualified than many of the professionals in Tajikistan, increasing her confidence in her ability to support her children, generating feelings of self-efficacy. The memory of how alone and confused she felt before the workshops has led her to reach out to other mothers in hopes of saving them from suffering through the same experience – a poignant story of motivation to build bonding social capital.

This discussion also shows the development of bridging social capital in the respect shown to this mother by medical professionals – an attitude mirrored by the physical therapist whom I observed working with the association. The way that outreach services are organized also gives some insight into how these mothers organize collective action and service provision. Even though some of their choices appear driven by Rangikamon, such as the final decision about who will have access to home visits, this warm relationship could also be providing face-saving cover for difficult decisions that protects the relationships between mothers as well as a pragmatic division of responsibility for fundraising – a strength of Rangikamon's director – freeing the mothers to work on service provision and continue learning about their children's disability.

Reaching beyond Khujand: New associations, old partnerships

In addition to building the skills of parents to supplement the acute lack of available specialists, the association in Khujand is dedicated to reaching as much of the Soghd region as possible. The founding mothers have worked with Rangikamon to expand and serve as many parents as possible throughout the region. At first, parents from the nearby districts of Chkalovsk (about 25 minutes by bus from Khujand) and Bobojon Gafurov district (about 45 minutes by bus) were coming to meetings in Khujand. After a few months there were enough parents to form small groups in each place, and they asked that someone from Khujand come to meet with them rather than directly participating in meetings in Khujand city.

Even these relatively short rides posed difficulties for mothers, either because of the cost of transportation, the time away from household duties, or the potential for gossip about a young woman who travels by herself to Khujand too often. At the same time, it is time-consuming and expensive for the association members in Khujand to travel to the districts outside the city. They can afford this only when they are able to raise funds, typically from a donor-funded project. Nazira discusses how she and her team supported these groups and helped them also register as independent associations.

> We started four initiative groups and when the project [supported by OSI Tajikistan] ended, we continued this work. We tried to visit other districts and meet with parents to start initiative groups even without project [funding]. They are like our children and want support from us. We included them in our meetings when Sabohat [Hakimzoda] organized them. I suggested that she also invite someone from these initiative groups to Dushanbe. (54-15-181)

Nazira asked the coordinating association in Dushanbe to include them in the Coalition, giving these new associations the opportunity for national recognition and access to donors and international assistance projects without direct mediation from their parent association in Khujand. This is an important indicator of good faith desire for these associations to be truly independent and successful

in the competitive NGO environment of Tajikistan that also speaks well of the Khujand association as an empowering organization (Maton and Salem, 1995).

In addition, the Khujand association has worked as a subcontractor of Rangikamon on a Caritas project that includes a component of setting up parent groups in four communities in Ganchi district. They have also supported parent groups in Spitamen and Kanibadam. These are not yet registered, but Nazira feels that they show some beginning signs of sustainability:

> We conducted trainings for the parents and worked with the children for a week. I think that it resonated well with them, and we developed together a small plan about advocacy activities that they will do in their own communities. Each group after the camp – during the camp, they made short films and afterwards they had mini-film festivals and a concert. They invited us and we went. The goal of the groups – we wanted to see if they would keep meeting after the project when there would be no formal meeting space or coffee breaks. Would they be sustainable and keep the groups going? I am very happy because the project from Caritas is almost over and they will not have any funding, but they still get together every two weeks. They exchange information with each other and maintain contact with us. Sometimes they send their parents to us if we have an event or if they need help with a specific child. (54-15-181)

The relationship between the association and Rangikamon continues to be strong and is not, on the surface, characterized by the sense of competition, hierarchy and resistance that is clearly evident in Dushanbe. However, this relationship continues to evolve. In each of these projects, Rangikamon has contracted Nazira directly as a consultant rather than the association. In some cases, this reflects a donor's preferences or regulations about sub-contracting. However, there are other indicators that Rangikamon views the association as an affiliate or 'family member' that is willing to contribute resources to its success. For example, last summer Nazira recounted how Rangikamon invited the staff of the association to work as volunteer parent trainers in a summer camp for 40 families:

> We conducted trainings for the parents and worked with the children for a week. I think that it resonated well with them, and we developed together a small plan about advocacy activities

> that they will do in their own communities. Each group after the camp – during the camp, they made short films and afterwards they had mini-film festivals and a concert. (54-15-181)

This took place within the framework of the Caritas-funded outreach project to Ganchi. As such, the association staff recognize that the overall relationship is profitable for them because of the access to parents and continued participation in international assistance projects that it provides. Volunteering is not necessarily indicative of a lack of other compensation or of exploitation of the association by Rangikamon. It is indicative of a close relationship where the director of Rangikamon, unfailingly referred to by honorific (*muallima*), is an acknowledged expert and elder. She seems committed to helping the association grow and continues to give them access to international assistance projects, including a recently submitted application for funds to work on CBR with an organization in Kyrgyzstan.

In the beginning, Sabohat Akimovna even helped Nazira to write project proposals to implement projects suggested or requested by parents. In turn, the association provides extra hands, access to its growing expertise and the network of trust and close relationships developed with families of children with disabilities. This symbiotic relationship is perhaps reinforced by their co-location in the previous office building of OSI Tajikistan in Khujand. Mothers define outreach to others as an important collective action, even if the location and structure is sometimes determined externally. It is clear that Nazira and the other founding mothers want to support these small initiative groups to grow in size and depth to the greatest degree possible.

Demonstrating the capacity to work independently on a collective goal, the association has built other partnerships with both DPOs and human rights organizations. Within the framework of the Handicap International project implemented through the League of Women with Disabilities Ishtirok, they worked with the three largest DPOs in Soghd region, the Society of Disabled People, the Society of the Blind and the Society of the Deaf, on documenting violations of the rights of

children with disabilities and an advocacy campaign to push for the ratification of the UN Convention on the Rights of Persons with Disabilities. This campaign included a component of accessibility of infrastructure, which has been picked up in the Coalition as one of their two strategic directions during the general assembly held in November 2015.

In addition, the Bureau of Human Rights and Law, a Dushanbe-based human rights NGO, interviewed association staff and members for research about the accessibility of education and employment for people with disabilities. They have leveraged this for the benefit of parents in the region, securing an agreement that the Khujand branch of the NGO will provide legal consultations to parents who are unable to engage their own lawyer. This is a respected organization that can provide protection for families, and, importantly, they have consultation points in Isfara and Bobjon Gafurov that will also work with the associations there. This is important even in terms of access to information about children's legal rights, as the association director in Isfara reported great difficulty in getting copies of regulations (*podzakonodatel'nyie akty*) from the local government, making their efforts to build bridging social capital across a deeply perceived thematic divide all the more important.

In speaking about the future, Nazira is proud of how far they have come as a group of parents and as an organization. By 2012, the association was serving up to 25 families per month through consultations and by 2015 they were serving up to 300 families regularly, so they have developed a great base of experience. Intuitively recognizing the process of empowerment, she is cognizant of the continued need to start from the beginning with each family as well as the need for the association's programs to grow with their children:

> We try to help our members as much as possible with their problems. We always ask them what they need, what they want. Children of different ages have different needs. Children under 7 need rehabilitation and access to a kindergarten. If the child is older, then there is the need to support him getting at least some kind of education and rehabilitation. It is also important to provide psychological support to mothers in particular. Mothers are in a difficult

> situation with these children, especially when the family, her husband and his family, her mother-in-law, don't support her. Sometimes they want to get rid of children with disabilities, send them to an institution. Then we work with the families very closely. It also happens that families fall apart, husbands leave and the mother stays alone with the child. Then she needs a different kind of support.
>
> Of course when we have these big public events, like the film festival, we try to show positive aspects of parents' lives so that other parents will be inspired, so that they will understand they are not the only ones who have a child like this and these problems. … I can see that our parents have changed a great deal. If we look back five years ago, how difficult it was, when not everyone thought that such an organization was necessary. When I see now how our parents' worldview has changed, how they speak with us – I am so happy.
>
> We have children older than 18 who have never had any education or anything. When their parents come to us and ask what they can do, how we can help them – it's a problem for us. We wonder if maybe we can do some fundraising for them or apply to the government for funding to open a small workshop for them. For example, groups for boys and girls so that they could make things to sell – as other organizations do. We just don't have enough time! We are only three staff members: me, Farangis and Nigora. (54-15-181)

There is a feeling of warmth and closeness among the members of the Khujand association who have been with it for several years. Mothers who are newer to the association appeared more focused on services for their children than on the activities of the association itself, although everyone interviewed noted that the seminars offered by the association were very important. They often referred specifically to seminars on legal rights or advocacy in this context. The founding members remain very welcoming and persistent in recruiting new members. It could be a matter of time before the newer members feel as comfortable and connected to the group. However, it is also possible that this association will experience the challenges reported in the Dushanbe-based associations of newer members viewing them as service providers rather than an association of mothers like themselves who also started from the bottom of the spiral, requiring support in return from parents to continue and grow.

Coalition leadership: Starring on the national stage

In contrast to the way that Nazira characterized her difficulties developing the parent association in Khujand as a completely inexperienced leader of an organization, she discusses the difficulties of coordinating the dispersed national Coalition in situational terms, acknowledging her own ability to cope. The Coalition is a group of 31 parent groups that has come together for mutual support and joint advocacy.

Every year, the Coalition members elect one organization to act as coordinator. The coordinating organization is responsible for leading and coordinating relationships with donors and national government, delegating tasks for the organization of the annual meeting and other Coalition-wide activities, and acting as leading partner for any projects that fund the Coalition as a whole. The organization in Khujand was elected to be the second coordinating organization, following the term of a Dushanbe organization. This set the precedent for rotation of this important role and served as a vote of confidence in Nazira despite her relative youth among the leaders of the parent organizations. Nazira explains:

> Last year we were elected to be the coordinating organization. Honestly, it was unexpected. We were not morally ready. We wanted to be in the Coalition, but when they said that we would be the coordinators, we were a little afraid. Of course, Sabohat Hakimzoda helped us a lot. Other organizations also helped us. It's team work. We also gained great experience that has helped us develop. Thanks to the Coalition, today I can say that I am very grateful that we were elected and that we could realize that project over the past year. In the beginning it was scary. We wondered if we could do it – with Khatlon and GBAO. They are so far away from us – would we be able to keep contact with them? How would we distribute funds and report on them?

In the end, the Khujand association met this challenge, perhaps informed by the process of developing other parent groups in the outlying districts of Soghd veloyat and supporting the association in Isfara through a leadership transition. They maintain their independence but have a close and positive

relationship with the NGO that incubated them, and they have not yet experienced the growing pains of the Dushanbe associations.

Sustaining the spiral of empowerment

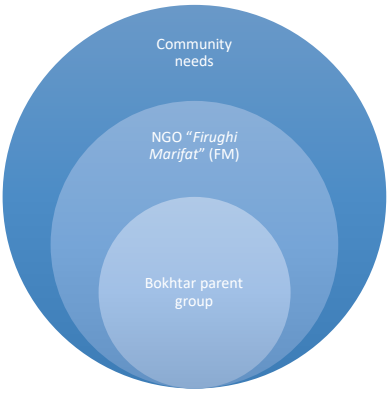
An orientation toward the needs of families and empowering mothers is important as one of the guiding principles of the association in Khujand. It is not the case in at least one of the daughter associations in Soghd and there are still challenges ahead. For example, the feeling in the Bobjon Gafurov association, about an hour outside Khujand, is very different. The director is the grandmother of two hearing impaired children. She has significant financial means and plays the role of matriarch within her family and within the association. Her orientation is one of help and social support much more than empowerment. For example, she very much wanted to be interviewed for this research and spoke at length about her life – both related and unrelated to her grandchildren and the association. She did not offer the opportunity to interview her daughter-in-law, the mother of the two deaf children, although she was present and I indicated that I would be happy to speak with her. During the focus group, she left the room to prepare refreshments.

The focus group indicated that the people present did not know each other well, sometimes asking each other basic questions about themselves and their children. They gather only for seminars with invited experts, in contrast to other groups where parents also spoke about celebrations and informal gatherings as well as the comfort that they took in talking to each other about their difficulties and sharing information. The director characterized herself as a person with the status and authority to bring experts (interview) and seems to act as a gatekeeper. There is potential within the group for more shared leadership, even within the small focus group that gathered for this research. For example, one mother had such strong feelings about inclusive education that she took about 10 minutes of the discussion in response to my question about potential audiences for association

seminars beyond parents themselves. She is a nurse by education rather than a teacher, but she felt comfortable enough speaking up and showed passion about the issue, making her a good candidate to lead the charge.

They have the model of an empowering organization and empowering leadership in Nazira. In some ways the development of these satellite associations foreshadows the difference in leadership, collective action, and critical awareness of the case study in Bokhtar. It also mirrors the difference between the associations in Dushanbe and those started with donor funds in smaller, more rural places.

Bokhtar: Empowered women with a mission for every donor



Bokhtar is a small town of about 8,000 people located seven kilometers from Kurgan-teppe, the administrative center of Khatlon veloyat. It was on the front lines of the civil war, witnessing some of the worst fighting of the late 1990's. Today the population is ethnically mixed as the result of migration and displacement. Most men are labor migrants, leaving behind families dependent on remittances but also making space for female leadership (Harris, 2004). The town center is organized along the main road to Kurgan-teppe with a perpendicular street between the World War II monument and the former main post and telecommunications office that leads through a neighborhood of neat, well-kept houses to the local school and athletic field.

The NGO "*Firughi Marifat*" (FM), which means *Additional Education* in Tajik, is located in the old post office. They have a small room used as an office, a larger room used as a library and meeting room, and the entryway that is used for coffee breaks. When I visited, they did not yet have plumbing and had to visit a neighbor's home for water or use of a latrine. Their mission is focused on rural development and women's livelihoods. They received funding in 2009 from the Open Society Institute Tajikistan to register the parent association and to provide for its initial needs. A focus group with the staff reflects these beginnings:

> Firstly, we have worked together in another organization "Furughi marifat." Our office was then in the house of our neighbor. She had a disabled child, and she lived without a husband, so we rented a room there to start our work. I [director of FM] was invited to a meeting [in the beginning of 2009] in Kurgan-teppe with Gulchehra [Kabilova from OSI Tajikistan] and Sabohat [Hakimzoda from the APDC in Dushanbe]. Sabohat told us about her activities. She told us how to open such an organization. We had no experience and did not know [very much about starting an association], but I used to work in Save the Children in Vakhsh and

> worked with such projects, with these families. Simply, those were not long-term projects. But, when I was working in Save the Children - then I saw a lot of families with children [with disabilities]. Then there was such a boost when Gulchehra and Sabohat [Hakimzoda] arrived. She said why don't you lead this organization, I'll help you. She approved my proposal. We have a lot of neighbors with disabled children. Bahriniso from Vakhsh was also with us [at one of the meetings], and now she's opened up their organization. Then we started working together – parent groups from Vakhsh and Bokhtar.

This recounting of the beginnings of the parent association portray a movement led by donors and outside activists from Dushanbe. Sabohat from the Dushanbe parent association and Gulchehra from OSI Tajikistan sought out the women of FM, who had seen disability in their community and had some experience working with people with disabilities but were not themselves mothers of disabled children. They pitched the idea of a parent association and the funding that could come with it. However, disability, previous experience, and male absence still play a role in this founding story. The original host for FM had a child with a disability, and the absence of her husband both made the space physically and socially for her to host the NGO and perhaps created the necessity for her to find respectable additional sources of income. This discussion shows a somewhat matter-of-fact acceptance of disability among people struggling economically and those with the mission of helping the community and draws on previous experience of FM staff working on social welfare projects and the connections that they have established with others, like the director of the parent association in Vakhsh.

All the same, this is quite different from the origin stories of the association in Dushanbe and Khujand, which began with mothers meeting each other through therapy groups or kindergarten programs and then evolving or building those connections into a formal organization, with outside support to be sure, but also with significant initiative from the mothers themselves. Asking an existing NGO not only to bring together mothers or to develop services for children with disabilities, but explicitly to start an association, was an attempt to grow the parent movement quickly in a new place,

hoping that the experience of empowerment could be translated or sped up – that the alchemy of mothers coming together could be planned by an experienced association director and dedicated donor if fertile ground could be found.

In some ways, Bokhtar is an encouraging setting for such an experiment. Having suffered from both the civil war and the 2010-11 polio outbreak, many families have personal experience of acquired physical disability. This carries much less stigma than disability from birth or intellectual disability, making it generally easier to open discussions about disability and inclusion.[12] Bokhtar is also a place that highlights some of the early difficulties and motivations of members within the Coalition of parent associations, reflecting the more acute lack of access to basic services in smaller, more rural places. Notes from an observation provide an example:

> This morning [May 15, 2015] I attended part of a workshop for parents and professionals on physical therapy for children with disabilities. It was supported from a project on early intervention and was conducted by two specialists from the PMPC in Kurgan-teppe. The leading trainer, Manzura Davlatova, is also the head of a polyclinic. There were nine mothers, one person from the parent association in Vakhsh, two staff from the Bokhtar association, and one doctor from Kurgan-teppe among the participants. Muttabat was upset because none of the local doctors or nurses from Bokhtar attended. During the seminar session, the trainers talked about using an ages and stages chart to think about the development of children with disabilities and also discussed ways to use everyday activities as opportunities for learning or development. They gave a demonstration of some simple physical therapy exercises and talked about how to make some basic assistive equipment at home.

In Khujand and Dushanbe, such basic expertise in physical therapy is available, whether developed by the parent association to a professional level or offered through healthcare facilities. This slightly shifts the focus from opportunities to interact with your child to providing basic care and practicing building

[12] During my interviews, six mothers recounted having met strongly negative reactions to their child with a disability from their mother- or father-in-law. Of these, five had a child with a disability that was evident at birth or in early infancy. In each instance, the woman felt supported either by her husband or her birth family. Only one woman listed herself as head of household, implying that neither her marriage nor her birth family was supporting her.

assistive supports from everyday items. This observation session, however, also reveals the similarity of struggles across all three case studies to gain family acceptance and to get fathers more involved:

> At the coffee break and during lunch, most of the conversation was in Uzbek. The group talked informally about the need to involve husbands and fathers with some women commenting that they have more support for working with their children with disabilities from fathers-in-law than their mothers-in-law. One woman recounted that her mother-in-law has forbidden her to take her child to the doctor, but she snuck out and did it anyway – a badge of honor in this group rather than a transgression. Now her mother-in-law has made peace with the idea of having medical care for the child and working with him at home. The woman expressed pride that she was able to help her child. Others echoed the sentiment that they would do anything for their children, whether fathers and other family members participated or not. They also talked about disability in religious terms, but more as a trial than a punishment. They had the idea that patiently bearing the burden of disability would be rewarded in the next life.

The informal discussions among the training participants pick up the themes of family opposition, bravery, and a dose of resignation that appear in other places. However, in some instances, there was also an interesting dynamic between the mother-in-law and the child's mother. One of the grandmothers who participated in interviews with me characterized her daughter-in-law as depressed and unwilling to care for her child with a disability:

> I would like my daughter-in-law to come here, but she doesn't want to go anywhere and asks me to do it. She says it is better for me to go because this is my son. My grandson loves me like his mother and I also love him very much. My daughter-in-law doesn't relate to him this way. She asks me to do everything related to my grandson – go to school gatherings, come here. I love him so much and all of his progress in terms of his health and education is because of me. Everyone around us, including my daughter-in-law, thinks this.

It is difficult to assess without knowing the family very well, which was not possible in the limited time that I was able to spend in this research site. However, the ways that transgression and disability intersect in Tajik culture means that it would be important to investigate whether the mother in question felt obligated (or was even compelled) to cede control of her child to her mother-in-law because she herself or others believed that her actions had some part in her child's disability. She could

also be wary of what others will say if she leaves the house unaccompanied to attend meetings or take her child to the doctor. Still, this grandmother clearly sees the child as able to learn and worth the investment. She also expresses feelings of self-efficacy, drawing a line between her efforts and the child's progress.

Overcoming stigma to access information

The leadership of the association characterize the first and most important step for any family as admitting that they have a child with a disability, both to themselves and to the wider world, so that they see benefit in meeting with other families and building a support network of connection to others. Surviving this socially and emotionally is the necessary first step on the empowerment spiral to increased confidence and pursuit of knowledge and finally the self-efficacy expressed by the grandmother. The staff of FM and the association understand this and work toward it intuitively by organizing workshops and seminars like the one described above. The difficulties that Muttabat, the director of FM and program manager of the parent association, expresses focus on the limitations of their resources and the vastness of need for help among families:

> The hardest thing is that it is impossible to do everything for free. No one understands us or thinks about these families. It took our local government two years to relate to us normally [as an organization]. It was hard for us in the beginning. People asked why these children [with disabilities] should go to school when we have to work with the healthy ones first. It was also difficult to reach out to families of children with disabilities. They were afraid. Some hid their children.

This speaks to the need actively to reach out to families and to share information with them, but foremost is the need to assure families that they are not alone and will not face stigma for their children in this association or among the others involved with it. Activities like the workshop as well as public holidays and celebrations and work with the media, have slowly combatted prejudice and have begun

to bring disability out of the shadows. However, the work of FM and its parent association may still be easy to misunderstand until a personal connection is made. This is evident when the association staff talk about their first steps in our focus group:

> Wealthy families refused completely, saying that their children did not need us and our services. They thought that we were offering financial assistance. Gradually they began to get used to us. But it is still difficult to reach all the *jamoats* (communities in our district) because our budget will not allow us to do so. When they come into the office, even if they are from other districts, we always advise them and help. And so basically we work in the center (Bokhtar town) and Mehnatabad jamoat. We once had a research project financed by OSI Tajikistan. We four carried out research [to identify families with children with disabilities] in other *jamoats*. We visited homes and found 50 families with disabled children in two villages. There the majority of children do not receive even a pension. They do not know where to go. They have collected and handed over all the documents are still waiting and do not receive a pension. Some children should be in school, but no one at the school can cope with them. Still, the parents are very eager.

The initial conditions of stigma and shame associated with disability are reflected here as well as ideas about what might be done to help and the eagerness of parents to make use of resources on offer. During discussions with the leadership of the association, they express satisfaction at some of the improvements that they see for families working with them, for example, noting that there are now very few who do not know how to apply for a disability pension.

Saodat, the current director of the officially registered parent association and project manager in FM, is able to devote significant time and energy to the association because her son is an adult and she is more senior within her family. However, she remembers well the difficulties and social isolation she experienced when her son was a child:

> I had many problems in life. At that time, [during the civil war] women did not leave home alone. If [a woman did this] there would be questions and doubts – where was she going, what was she doing. The neighbors would gossip about her, and of course, the woman would be ashamed. I tried not to pay attention to any of this. If someone asked me where I was going when I was bringing my son to the hospital or somewhere else, I would tease them that I was

> going carousing (*пошла погулять*). People even suggested that I was using my son as an excuse to go to the city every day, especially because my husband was in Russia then…. Now when my son comes home from Dushanbe, everyone in the neighborhood praises him. They congratulate me for working so hard to make sure that he studied well.

She was able to do this because her husband and father-in-law were both absent, working in Russia. This left Saodat and her mother-in-law alone during turbulent times, ensuring that they needed each other's support equally. Neither was in a position to risk the other leaving for good, so Saodat had much greater freedom than might have been possible if the family had been together.

Although Saodat is clearly empowered and proud of her son, it is difficult to tell whether there is a process of empowerment taking place for others in the way that our theoretical model would define it. Access that the association provides to information and people in Dushanbe, viewed as a progressive urban area with greater resources and sophistication, is an important way for the association to establish its own credibility, to help parents feel connected to a larger group with similar problems and concerns, and to offer an alternative to stigma and shame usually associated with disability. During the focus group, one association member described a particularly moving meeting where the director of the parent association from Dushanbe told the story of her child openly and without embarrassment:

> When we started working in Mehnatabade, we were walking home to home to find out how many of these children [lived there]. We invited them to our seminars, we had a workshop on children's rights. Sabohat [Hakimzoda, director of the APDC in Dushanbe] came to the seminar and told her story. Parents began to understand a little bit after that - you have to accept it all. Here I have one neighbor who had a child with a disability, and her husband and mother-in-law did not want this child to register for a disability pension. Then we have this mom invited to the seminar. There are of course those of the family who are opposed or ashamed and we try to attract them to our organization in different ways for their own good.

The way that this mother frames the conversation is central to the questions of empowerment and collective action. On the one hand, she indicates the power of shared experience, of understanding that you are not the only mother struggling to raise a child with a disability. On the other hand, she

succinctly expresses a desire to push people into a specific course of action 'for their own good' – a potentially disempowering way of working even if it comes from the best intentions. Thus, the research questions shift slightly in this case to ask whether this effort to jumpstart empowerment among mothers in Bokhtar is empowering and how it has played out over the six years between initial contact in 2009 and this research in 2015. Is there evidence of individual empowerment, increased social capital, and collective action or setting of priorities among the mothers in Bokhtar that is reflected in the activities and structure of the association?

There is certainly a beneficiary relationship between the association, demarcated by its staff and 2-3 most active associates, and the rest of the parents participating in this research. This may be a result of the organization's access to international assistance and government resources. The ability to work within these systems and, sometimes, to intercede directly on behalf of families with particular challenges positions the organization to be viewed as a source of benefit. However, this access to resources is a double-edged sword creating the incentive to reach as many people as quickly as possible without necessarily consolidating the relationship or prioritizing membership over more superficial types of participation.

The first group of interviews conducted in Bokhtar consisted almost entirely of women who were visiting the association for the first time. Although they cannot reasonably be considered members of the association, they did provide some context as well as a newcomers' perspective of the invitation to join an association. My first research visit was timed to overlap with a workshop, so it is understandable that the staff wanted to use the opportunity to reach out to new families. Although not everyone invited to interviews participated in the workshop, there was an atmosphere of support and acceptance. It is significant that parents of children with many types of disability are welcomed into the group.

The starkest and most heartwarming example is the mother of a preteen transgender girl with Down Syndrome who was invited to interview with me and took part in the association's workshop. It is difficult to imagine a more stigmatizing set of identities in Tajikistan, yet this woman was welcomed into activities on the same basis as others, including when she brought her daughter with her. She explains her concerns and the support she has received eloquently:

> They help me all the time. When my child was small, she couldn't walk. To get medical care for her, I had to take her to the hospital in Kurgan-teppe. I had to carry her there in my arms from Bokhtar [about 7 km away] because we didn't have the money for transportation. With help from the UN, her treatment was free and thanks to that she is now able to walk. My daughter has the type of character – she always wants to dress as a boy and doesn't want us to call her by a girl's name. She even wants a beard and mustache. I am really worried because soon she will enter puberty and start to menstruate. What am I going to do? How will I explain this to her?

This mother has a very clear understanding of the challenges ahead, although she did not have the vocabulary to name her child's transgender identity. She told this story freely in the coffee break area of the workshop, well within earshot of others. She then participated in the workshop and even had her child demonstrate some of the exercises that they had done to support walking on the trainers' dummy – a rag doll about the size of a 6-year old child. This speaks to a sense of safety and connection, indicating that FM can create an empowering environment even if they are not necessarily driven by the collective action of parents.

During my second visit, I met the majority of the people who had been involved in the association's activities for a longer period of time. No one discussed her own contribution to the association or expressed a sense of responsibility for its governance or continued existence, although everyone expressed gratitude for the opportunity to attend workshops and learn about services for the children with disabilities in their families. It also seems that there may have been a hiatus in outreach to potential new members, as interview participants either said that they had been coming

for 3-4 years at Muttabat's invitation or had been referred by one of the two teachers active in the association, if they had not come for the first time indicating that outreach, although viewed as important, is dependent on fundraising in rural areas where transportation is expensive.

Despite the irregularity of membership and member participation, FM and the association are offering the types of opportunities that supported empowerment over time in the other cases. The majority of mothers and grandmothers who had been more than once to the association's events (6 out of 10) noted the benefits of being with other parents like themselves and the social outlet for their children as important. Two mothers describe this during interviews:

> Before I tortured myself, worried, and blamed myself for having a child like this. I thought I was the only one. After I started participating in this association's activities, I changed a lot. [It was important to] see other mothers with disabled children. We became friends within our bitterness (*подруги по горю*).

> I used to take my daughter to doctors for treatment all the time. She couldn't speak, and I was going to cure her. At that time, I would cry because my daughter was like this. One day, I met a woman [from the association] who also had a child with problems, and she shared her experience with me. You could say that she explained things to me. Now we have stopped going to doctors, stopped looking for a medical cure. Participating in these seminars, meeting with other mothers – I have stopped torturing myself. I have stopped crying. I finally understood.

The sentiment that the difficulties of raising a child with disabilities become more manageable when you know others who are in the same or even more challenging situations was reflected in nearly every interview, as was the importance of learning to help and support their children. These are both elements that lead to increased confidence and connections with others – the beginnings of self-efficacy and bonding social capital.

My observations also speak to a caring and friendly relationship both among the association staff and the wider constituency of mothers benefitting from their work. People waiting to participate in interviews and joining the coffee breaks during the workshop were engaged in lively conversation,

inquiring after each other's families and speculating whether the new café across the street would be successful. There is evidence that the people I interviewed and observed value spending time with each other and enjoy each other's company. They came to the workshops in their best clothes and brought food to share, laughing together and talking well after the end of organized activities. In the words of one mother, these activities are a place where mothers can "relax and escape their problems" (14-166). Many also referred to others they had brought with them, like this mother:

> Not long ago I brought my neighbor here with me. She has a child diagnosed with cerebral palsy. She was just sitting at home and didn't know anything. So, I brought her here…. I also stay at home [as a housewife]. Coming here, I have learned so much.

Empowerment in this case is more visible in the early stages of learning concrete strategies and activities to support children with disabilities and negotiating greater acceptance of the mother and child with disabilities within her family and the importance of moral support from others, indicating some development of bonding social capital. This mother also indicates the value of learning about disability through the workshops and activities of the association:

> At these seminars, we learn how to take better care of our children, how to work with them. But most important for us, we see that someone besides us cares about our children…Most importantly, I have begun to understand my daughter better.

The importance placed on not hiding children with disabilities at home and the participation in public events gives clues to the difficulty of this journey. One woman in the workshop commented that her mother-in-law had forbidden her to take her child to the doctor, but she decided to sneak out and do it anyway. She said quite proudly that her mother-in-law had made peace with the idea of the child with a disability receiving medical care and was willing to let her work with him at home. Another mother talks about her commitment to her child:

> The way it is here, of course my husband's mother isn't happy. Neither is my husband. I do everything for my daughter myself. I sold all my jewelry so that I wouldn't have to refuse her anything and so that I could get her medical care.

These are no small victories, representing initial defiance of their mothers-in-law's wishes and further winning the day by taking time from household duties to work with their children.

There is also some indication that learning about disability and ways to support children with disabilities has supported important elements of empowerment among this group of women. First, learning ways that children with disabilities can be supported through physical and other types of therapy has given them an antidote to the hopelessness with which the medical community delivered the initial diagnosis. They know that they can do something that will make a difference to their children, including specific strategies like using everyday activities as learning opportunities or using inexpensive items found at home (like pillows or cardboard) as a substitute for physical therapy equipment. One of the mothers who has participated in several association events tells me:

> These seminars are so useful. When I find out that there is going to be a seminar, I call other mothers like me [with children with disabilities]. I am so grateful to the people who give these seminars.

The mother expressing her gratitude underlines the utility of the seminars as places to learn new skills and information that supports her relationship with her child. However, her expression of gratitude also underlines the client-beneficiary relationship described by many of the mothers interviewed. Rather than seeing the association as something that they must build and sustain, they see the staff of FM and the association as gatekeepers to expertise or experts in their own right who provide a service.

Similar respect from the local medical community is slower to materialize. The staff of the association have expressed frustration that none of the doctors or nurses from the local clinic, which is located less than 200 meters from the association office - quite literally across the street - could make time to attend the workshop despite the presence of two respected professionals from Kurgan-teppe. Both the respect of mothers and the disrespect of doctors are distancing in their own ways. With the mothers, FM will have to turn the connection of shared experience and desire for learning

into a shared sense of collective action to be sustainable. With the doctors, additional bridging social capital needs to be built.

Finding families and addressing needs

Although the association needs to have funding for travel costs, their choice to reach out to families of children with disabilities through home visits is essentially offering a path into a social capital network that includes others in similar situations but also access to concrete resources. This certainly includes health and education services, but it could also include temporary employment and humanitarian support, depending on the types of donor-funded projects that the association and FM are implementing at the moment. Attention from women who have become community leaders helps to confer status that may have been lost after having a child with a disability. This inhabits a space between social capital construction, collective action, and donor-driven projects. Saodat and Muttabat describe the process of building a network of families around the association eloquently:

> We do not have a large area. We all know each other, and we have neighbors with such problems. In the beginning when we started working, we worked with 8 families. Then word-of-mouth about our organization went throughout the area, at weddings and at different events because guests [participants] began to speak about us because they themselves are the parents with disabled children. Muttabat has two nieces, they do not hear, like the son of Saodat. For nine years Saodat drove her son to school in Kurgan-teppe from this village. I was very surprised. I admire her, what she did with her son, despite the talk of neighbors and relatives of her husband. The only thing that helped her was some support from her mother in law.

Most of their support to families involves navigating the systems of public services, in particular registering for a pension. Although small in absolute terms, the 130 TJS (about $15 at the January, 2018 exchange rate) monthly pension represents a large relative increase in income for many families. The registration for a pension is important to parents, but also leverages bridging social capital built during the implementation of rural development projects. The staff members of FM/parent

association are well-known to the district administration as advocates with links to international assistance, making it easier for them to assert families' rights to pensions, education, and other benefits. Saodat explains:

> Yesterday a mother came because she heard about us from a neighbor. She had a problem and decided to come to us for a solution. Her daughter, who was studying in the 8th grade, became ill. She was paralyzed [as a result of the illness] and could not walk. The mother wanted her to continue her studies. I explained everything to her and promised to help her write a letter to the Ministry of Education if her daughter wanted to study in school rather than at home. She was surprised that we would do all that for free.

Saodat knows how to navigate the system and has the contacts to do so. This is an indication that some bonding social capital is beginning to form, as mothers reach out to one another and bring them into contact with the group. There is an interesting relationship between wealth or economic status in the community and willingness to acknowledge disability. Saodat talks about "families in our village who have no financial problems but they have children with disabilities, and their children never leave the house." Families who have greater wealth and social status may feel that they have more to lose by admitting to having a child with a disability. As a result, they may be less willing to consider the idea, preferring not to forge connections because they do not have the material or financial need and may still have access to other social capital networks – a possible link between poverty and the potential for collective action in the parent network.

This is a significant difference from history of parent groups in the West, which often have been started by more affluent parents (Bertelli et al., 2009). The associations in Dushanbe more closely mirror this Western experience, as the founders are all financially secure and well-educated. This has implications for the association's potential access to resources in the community. At the most basic level, wealthy members of the association could become patrons supporting services or programs for others, like the wealthy mother in Dushanbe who has started a kindergarten to welcome the children

of other SiDa members. However, research indicates that education and access to financial resources also imply better access to social capital networks (Gibson & Woolcock, 2008). Mothers with more humble backgrounds may face greater obstacles building the bonding social capital that precedes collective action on the empowerment spiral.

All the same, there is evidence that there is some effective outreach from the association with multiple examples of mothers bringing others into the group through word of mouth and the staff of FM and the association using travel funds they raise to go house to house in new districts. Concurrent with these efforts are actions that seek to begin building bridging social capital. Muttabat explains:

> Our moms hear from each other about our organization and come themselves. We also shot a video and have shown it on [the local channel] TV Safina. Our progress in our affairs was that we have attracted families who have children with disabilities to schools and kindergartens. Now they are able to show themselves and be involved in the activities. We held a competition that was attended by representatives of the government and of the Ministry of Education, and they, too, were convinced that they are able to include all children. It will soon be June 1, which is the day of protection of children, and we plan to hold a marathon. April 4 was a festival in the city of Kulob. We took 10 disabled children with their parents [unfortunately] at their own expense, because we do not have sponsorship.

During my field research there was further evidence of bridging social capital through close cooperation with the PMPC, including organization of a workshop on physical therapy led by two staff from the Kurgan-teppe PMPC in the association's office. There was also evidence of continued cooperation with the local government. During a meeting between the association staff, the deputy mayor of Bokhtar and senior staff from the Open Society Foundations in June 2015, the deputy mayor indicated that the director of the association visited often and was not at all shy about asserting the rights of the association or the families of children with disabilities. Although she joked about wanting to hide when the association staff came calling, her positive demeanor and supportive comments in the presence of high-level visitors from an important donor demonstrated pride in the association's recognition and respect for Muttabat and Saodat as colleagues.

Between social capital and collective action

The presence of the nascent social capital networks explored in this case study begs the question of how these important resources are mobilized beyond reaching out to families to provide individual support for children and whether these activities represent collective action. The association and FM have expanded their activities to include a focus on education, perhaps because there are at least two teachers closely affiliated with the association, including the current director who teaches at School #20 and a teacher working with children with disabilities at School #26.

This logical entry point combined with the difficulty and expense of transportation to Kurgan-teppe and the possibility of support from international donors has made work on education programs more attractive. Although most of the mothers interviewed appeared to be following the lead of the association rather than collectively acting to advocate for inclusive education programs, at least Saodat is firmly behind the idea of inclusion regardless of the availability of donor funding. Part of this focus on inclusive education comes from the experience of her adult son who studies in Dushanbe:

> Our goal is to bring these children into society so that people see them rather than discussing [gossiping about] them. When I visit my son in Dushanbe, I can see that he is the only student with a disability in his college. He studies well there. It makes me so happy. When I see him there, I cry from happiness.

She draws a clear line between inclusive education, social acceptance, and opportunity, which explains why she is an enthusiastic advocate but does not explain how she secured support from the school for a resource center to promote inclusive education.

The association's current work in education, focused on creating a resource center in School #20 with funding from OSI Tajikistan, is affected by the context of the school beyond the personal relationships linking it to the association. This school was on the front lines of the civil war. Bullet scars are still visible on one of the outside walls. Funds for renovation of the school since it re-opened

have come largely from the local community. The school principal does not seem to be well-connected to the local political elite or the international development assistance that such connections often bring, although he is well-respected by parents and teachers. Thus, he is firmly a part of the community but not so powerful that he does not see the need for help from others, making him a perfect ally for the development of bridging social capital.

As a result, a grant that provides funds for the renovation of a classroom still suffering damage from munitions is very attractive regardless of any prejudice against people with disabilities. Furthermore, this work places the school on the map for international assistance, perhaps allowing the principal to seek further funding from other donors. The coincidence of the grant-recipient parent association's director also working as a trusted senior teacher at the school could be the catalyst for the location of the project but, alone, might not have been sufficient. In addition to facilitating the project, it also makes Saodat a resource for the school beyond her position as a teacher, increasing her power and prestige. She is able, through the association, to bring international assistance into a school that heretofore has not had significant access to such funding.

The association and school staff set the initial goal of preparing 6-8 children for participation in inclusive classes. This was not a specific requirement in the call for proposals that OSI Tajikistan released, which refers only to support for access to quality education for children with disabilities. In 2015, the parent association had funding from UNICEF and a grant from OSI Tajikistan to set up a resource center for inclusion of children with disabilities in School #20.

The example of this resource center shows an interesting intersection of local interests and donor plans. The staff of FM and the association are able to mobilize the social capital networks built through their work with parents as well as previous engagements, such as Muttabat's work with Save the Children or the rural development projects that FM has implemented for the World Bank. In the

end, the push for each of these projects, including the resource center for inclusive education, seems more like action by 2-3 people that is collectively endorsed by the community members who form the constituency of FM and the parent association. As Muttabat acknowledges earlier, it is impossible to do everything for free. Making compromises or re-prioritizing projects based on the availability of donor funding makes sense as long as there is sufficient community endorsement for them to be successful – a mix of internally and externally defined collective action. However, Muttabat also notes that "no one understands or thinks about these families." She sees part of the mission of FM and the association as changing this state of affairs by raising awareness and asking families to come out of the shadows, indicating a nascent critical awareness.

In some cases, like this one, there is still significant opposition that must be overcome by leveraging bridging social capital. This would not be possible without support from teachers and other school personnel. A mother tells her daughter's story:

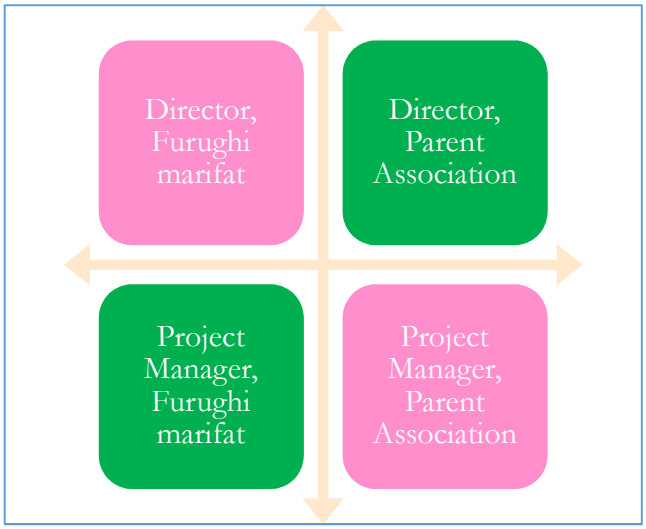
> At first the teacher wouldn't accept her into first grade. She said that my child couldn't write and had no talent for studying. She sent her home. I worked with my child at home, and for some reason, that teacher left the school. The principal called my daughter to school again so that she could continue her studies, but my father-in-law didn't want her to study. He took her to Dushanbe and had her assessed. Once he had those certificates [of disability], he said that she should not go to school. All the same, at school they [the principal and new teacher] kept asking us to send her, regardless of the certificates. Now everything is good – she studies at school and everyone has a good relationship with her.

The simplicity of this mother's recounting belies the tenacity of her resistance to her father-in-law and her fierce belief that her child is capable of learning and studying alongside other children despite the first teacher's assessment. Without continued support from the principal and the second teacher, it is unlikely that the child would be in school. A second mother indicates an often-expressed desire for education in the community school and creative solutions for access to education close to home in a regular school:

> She [my daughter] studies in the third grade. Although there is a large age difference between her and her younger brother, they study together. She likes school. Everyone is kind to her there.

However, regardless of parental desire for education for their children, the concrete plans for developing the resource center have come almost exclusively from Saodat, another teacher active with the association (although not herself the mother of a child with a disability), the school principal, and staff of Open Society Institute Tajikistan. There is no evidence that even the mothers of the children to be included in the school have played any role in designing or thinking through the resource center. The question of the balance between the goals and desires of mothers on the empowerment spiral, the pre-cooked plans often advanced by international assistance, and the history of the association as part and parcel of a local NGO, FM, that is funded by grants from development projects shines brighter in this case than either of the others. Where do projects end and collective actions begin? The development of the association from an outside perspective offers some clues.

One organization, several hats: Maintaining the mission



The crosswise structure where Muttabat is both the director of FM and a project manager in the parent association; Saodat is the director of the association and a project manager at FM. One accountant is bookkeeper, office manager, and project assistant for both. Both the parent association and FM continue to use the same office space and implement projects together, over the last five years, acquiring office equipment and moving to government-provided space in the former telephone/telegraph office near the central square. Their promotional materials highlight the missions most favorable to donors – agricultural

development and water rights for the World Bank, rural development and women's livelihoods for Save the Children, and education and inclusion of children with disabilities for the Open Society Foundations.

Legal registration's effect on the development of the parent association is important because of the role that it plays in others' understanding of the organization in ways that support or deny access to funding and learning opportunities. For example, commenting on NGO structure in her report to the Open Society Foundations, Jo Baker writes, "currently one or two are being nurtured by NGOs who also provide accommodation and access to resources and support. For most groups this is vital in the early stages of development and aids growth and learning. However, in the longer term independent registration is useful for funding purposes and to ensure the work is focused and truly led by parents" (Baker, 2010). In her eyes, incubation and co-location a temporary situation that could compromise parent empowerment if continued too long.

During the formal focus group, all three core staff members skirted questions about the relationship of the two organizations and the points of divergence or convergence of their missions. They understood that the complexity of institutional arrangements and initiatives they were developing could be off-putting to donors, or even portrayed as a form of corruption or misuse of funds. They did not want to say anything that could damage these important relationships, but also understood that there is no path to setting up and supporting individual organizations, including a parent association, with sufficiently narrow missions to appeal to each funding source.

In fact, Bokhtar is a small place where the families who have difficulty sorting out water rights might be the same families with female-headed households in need of sustainable livelihoods to sustain them between the remittances sent from Russia (or sometimes in the absence of remittances as men remarry and start new lives abroad). The families affected by disability are the same families trying to

develop small farms in a harsh climate. Being the parent of a child with a disability is only one part of the identity of the women who look to FM and the parent association for help, and it may or may not be the part of their identity in the most urgent crisis. There is enough overlap in these identities in an already small population to make the shared leadership and registration model of FM and the association make sense.

Through hard work and savvy, the leaders of the association have developed relationships with local government and are effective enough that one district official told me when she sees Saodat (director of the association) coming into her office, she knows that she will have at least one problem to solve by the end of the day. Muttabat and Saodat have positioned themselves as a channel for international assistance and resources, working to translate the narrow focus of donor projects into something useful for the community as whole in full recognition of each family's multiple layers of identity. These include the skipped generation households where grandparents are caring for young children because of labor migration, families affected by lost loved ones from the civil war, families who were forced to migrate from other parts of Central Asia in the last generation, families living in poverty, and families affected by disability. None of these identities is mutually exclusive and all may need some type of support. At the same time, the size of the population and the assistance available is not enough to support an organization with an exclusive focus on any of these identities.

Although the parent association exists legally as a separate organization, the two NGOs operate as a single organization. It is also clear that, while the staff respect each other and all contribute to the greater organization, the director of FM is the de facto leader. When there are meetings of the Coalition of parent associations, the director of FM travels to Dushanbe to represent them rather than the formal director of the parent association. At the meeting in November 2015, she was elected as one of two representatives from Khatlon to take part in the governance of the Coalition of parent

associations, marking her as both the leader of the parent association in Bokhtar as well as among parent associations in Tajikistan.

The subordinate position of the director of the parent association within this NGO structure is reflected in Jo Baker's report, leading her to recommend greater independence so that the parent group would become a 'real parent association.' In the reality on the ground, this appears unlikely in the foreseeable future, begging the question of whether parent empowerment can take place within this structure over more time and where it might lead. After an assessment visit to Bokhtar undertaken at the request of OSI Tajikistan, Baker (2010) writes:

> The staff demonstrate a great passion and commitment to work with these families. The organization has a clear understanding of what they want to achieve and the focus of their work. They were able to work quickly and effectively together to create an action plan of activities and outputs/outcomes for the project. The Director is lacking in confidence and experience but learnt quickly and even in a few days I saw her grow in knowledge and confidence. The way the new association is supported by the existing NGO is positive and constructive, empowering [the director] and the other parents. (pp. 3-4).

The overall assessment provided to OSI Tajikistan in 2010 indicates that this organization is, indeed, quite strong, although it would be a long stretch to define their activities as the collective action of empowered parents, even if they are broadly supported by the families that they touch and connection with the association is seen to be a source of social capital to draw upon during times of difficulty. This assessment is also borne out through my own observations five years later, with the exception that I do not find the director or other staff to lack confidence.

With little evidence of critical awareness beyond the family structure, the association in Bokhtar is more focused on making the existing system function than the associations in Khujand or Dushanbe. It is also more limited by lack of resources, including qualified education and healthcare

professionals, locally. Saodat is cognizant of the deficit and canny about the limits of the school and the association to sustain community support:

> [In School #26] they have a common classrooms. The healthy children and those with disabilities study together. Probably the parents wanted that type of a mixed classroom. My students are different – their disabilities are more profound. That's why it's easier for [the teachers] at the other school to mix all the students together.

The motivation of the leaders of this particular association for engaging in inclusive education are complex. The topic itself is listed on the agenda of several donors, making it an attractive proposition for bringing funds into the organization. This is certainly one motivation. Another is the understanding that mutual support among women or parents sometimes it is still not enough. For example, the director of the parent association has changed since registration in 2010 but is still a parent. The first parent was unable to cope with the demands of the work and her home life, as her child, who has complex physical and intellectual disabilities, grew bigger and more difficult to care for. She has placed her child in a boarding school and has negotiated herself a job there, effectively putting them both in an institution, removing them from the community.

The connection between the association director and the school is also important. But the mothers interviewed in this sample by and large wanted educational opportunities for their children. Several parents expressed worry about what would become of their children as they got older and saw education as a way that their children would be able to take care of themselves more effectively. Many also expressed fears that their children would be bullied, that they would not be able to keep up and that teachers either would not be able or would be unwilling to support their children's learning. The distance to access special schools and the lack of trained professionals nearby combined with their trust for the two teacher-members of the association makes families more willing to send their children to a local mainstream school.

The initiative is based on the needs and demands of parents as these are interpreted through the association's structure within FM. Thus, the headline activity of the association cannot be characterized as independent collective actions of empowered parents. However, it is abundantly clear that the formally registered association is the initiative of a small group with an interest in access state services, economic well-being of their community, and issues that affect women and children in a community where men have largely left to find work as labor migrants.

Conclusion

Empowerment does seem to be taking place but is in the earlier stages of developing knowledge, confidence and feelings of self-efficacy that allow for the rebuilding of social capital within families and society. The bonding social capital among mothers does not appear to be as strong in terms of acting as a facilitator or catalyst to collective action, but the warm welcome provided by this NGO and its role in mitigating the stigma of disability may make this less important, particularly in a small community where families know and depend on one another. This very dependency may serve to keep more mothers within existing social capital networks. As families struggle to make ends meet, it is more difficult to cast anyone aside, regardless of their transgression. Remember the example of Saodat and her mother-in-law, joined by economic need for each other in the absence of both their husbands. The contribution of this case is the intricacy of the organization's response to international assistance opportunities and donor priorities. The dedication of all three staff members to bringing together the community and serving the needs of women in challenging circumstances is evident throughout.

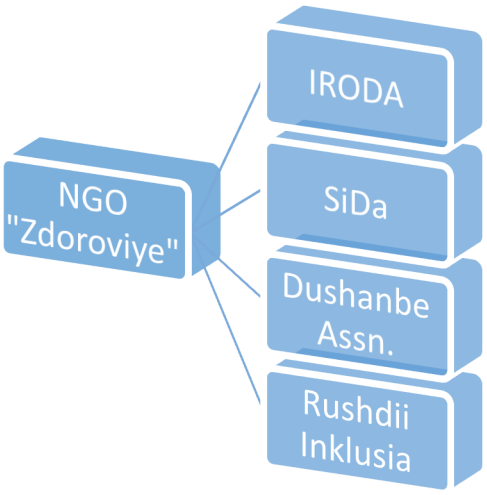
Although the staff's ability to raise funds and work with a variety of international programs leads to quite a strong advocacy position with local government, it stays within the existing system pushing for the implementation of the rules as they are. In this sense, there is not a political mission

to change the system. Muttabat exhibited discomfort with this concept in conversation with the leaders of other parent groups, much the same way that she was uncomfortable with questions about the ways she had worked to make international assistance projects effective almost in spite of themselves.

If these women are political, their actions are quietly subversive – visible in their warm welcome of a transgender child with Down Syndrome without fanfare as though any other community would be equally as welcoming and their efforts to bring children with disabilities into the school where they have the best connections. It is significant progress that families are willing to participate in public activities with their children, even when they have to raise funds within the family to do so, and contemplate sending them to school.

As elaborated above, this association acts much more like an NGO whose activities are based on the funding that they can access, although some activities that do not involve monetary costs, like offering consultations in their office to those who seek them out, continue regardless of project funding. It would be difficult to make the case that this association is parent-led or represents the collective action of parents of children with disabilities. The same may well be true of other, similar associations established with small grants from UNICEF and the Open Society Foundations through incubation within an existing organization. In this sense, this organization is not a 'true' parent association. However, that does not mean that it does not support empowerment or the formation of social capital among parents of children with disabilities. In chapter 5, we will turn to the similarities and differences across these three case studies. It could be that the parent association in Bokhtar is much closer to the early stages of its development as an empowerment process for mothers.

Dushanbe: Common roots, divergent experiences



Dushanbe has been the capital of Tajikistan since 1924. At the time, it was a small village with a Monday market, indicated by the name Dushanbe, which means Monday in Tajik. Called Stalinabad from 1929-61, Dushanbe was part of Stalin's plan to create a Tajik SSR separate from the previously powerful emirates of Bukhara and Kokand, which were placed across the border in the Uzbek SSR. It has remained the capital ever since and today has a population of about 800,000. Dushanbe is also home to international embassies, multilateral aid agencies, and iNGOs, giving the city's residents an important connection to global expert communities, commerce, and international assistance funds. The relative wealth and size of Dushanbe can generate competition for resources. The associations in Dushanbe have the most tense relationship with their incubating NGO and have sometimes had conflicts with each other.

This is the story of empowerment in a potentially disempowering setting and the strong bonding social capital that has grown among mothers of children with a range of disabilities and challenges. In the original research design, I planned to work only with IRODA as a research site. As a disability-specific association, they would complement the other case studies. However, as my research progressed, respondents in all three sites highlighted that ways that their experiences differed based on the timing and cause of their child's disability assessment. Further research in Dushanbe, home to three parent associations and one parent-led NGO, offered an opportunity to expand the interview sample to explore questions around the timing and type of disability while continuing to fill out the history and evolution of the parent movement overall. In addition to interviews and focus

groups with 19 parents at IRODA, I also worked with 17 parents at SiDa, the association of parents of children with Down Syndrome.

There are two additional parent organizations located in Dushanbe. The Association of Parents of Disabled Children, directed by Sabohat Hakimzoda and an important character in the Bokhtar case study, is open to parents of children with any type of disability. This association has a close relationship with several of the associations in Khatlon veloyat and the Region of Republican Subordination, which Sabohat helped to set up with funds from UNICEF and the Open Society Institute Tajikistan. References to the Dushanbe APDC are included throughout the research, but in the interest of limited time and resources, I decided not to develop a case study or include it here because the cases in Bokhtar and Khujand both focus on general disability-related associations. Rushdii Inklusiia is an NGO founded by the mother of a profoundly disabled child with the purpose of supporting children with disabilities to study in School #29, a mainstream school. Although founded by a parent, it is not a parent association and is not included as a central actor in this case study.

Both groups of parents from IRODA and SiDa told stories of a different type of heartbreak that is recounted more fully in Chapter 5, but is also relevant to the process of empowerment and useful in providing the context for parent groups developing in the national capital. Parents of children with autism recounted the experience of coming home from the maternity hospital with a 'normal' child, often a celebrated son. As their child reached 18-24 months, he would begin to exhibit odd behaviors and regression in speech and other domains of development. This would begin an odyssey of visits to clinics, doctors, and other specialists that typically resulted in confusion, misinformation, and depression before an assessment of autism and referral to IRODA. One mother tells a typical story:

> I went to other places – to doctors and professors – but they could not help. I would ask them why my son behaved that way and they would shrug their shoulders. They didn't know anything. I came here [to IRODA] and asked questions, and they answered all of them. They knew everything. I found everything I needed here. IRODA is the only place where my son has been truly helped.

Those who arrive at IRODA are typically referred by a doctor or medical institution (often Polyclinic #12) after a long, arduous path to the diagnosis of autism. Another mother shares a similar story:

> When he was a year old, he spoke a few words, danced, sang. Step by step, he stopped doing those things. It was hard to notice at first…My husband told me not to worry, but I already knew that there was something wrong at the age of two… I took him to doctors, and they said that he had inter-cranial hypertension. I don't know if that was right, but we treated him for that… [Then]I took my son to Polyclinic #12 and they told me to come here. They could not tell me whether he had autism or not.

Parents of children with Down Syndrome typically become aware of their child's disability at birth as healthcare workers inform them with varying degrees of cruelty and stigma. One mother tells a common story through tears:

> I came here and they talked to me – told me that I wasn't alone. That there were many more mothers like me and many children like mine. I found out that my child is not like they told me at Maternity Hospital #1. The doctor told me that my daughter would be like a dead person, like a corpse. She would never talk or walk and that there was no cure for her.

Thus, for some parents IRODA and SiDa are a lifeline to others in a similar situation, although myriad challenges still exist. For others, their family acts as a lifeline in the face of stigma, gossip and self-doubt.

The difference between these two experiences is initially stark. A mother of a child with Down Syndrome may be overwhelmed with feelings of helplessness, fear, and despair about her child's future from the maternity hospital. By contrast, parents of children with autism begin their journey with hope, often looking for a cure that proves elusive, before succumbing to depression and despair, and hopefully, moving forward to acceptance and empowerment. Although this process is now taking

place in two different parent associations with limited contact between the groups of parents, the founding members share a common history that has contributed to the ways that they have established these associations and influenced their leadership more broadly, including participation in the national Coalition.

Common roots: Tension and conflict, control and subversion

The parent associations in Dushanbe started somewhat earlier than the others and grew from mutual connections made through Venera Mirzoevna, director of the NGO *Zdoroviye*. The name of her organization, and it is very much 'her' organization, means health in Russian. Since all four of the parent organizations in Dushanbe grew in one way or another from her work and remain influenced by these origins, it is useful to understand how they first came together and how she characterizes the ways that she first became interested in childhood disability and parents of children with disabilities:

> It was in 2001 when I went, completely by chance, to Bokhtar with Save the Children – specifically the part of Khatlon where the civil war was very active. We saw there many children with disabilities. We went there just to see what we could do, and I was shocked. We saw that the combination of the war, poverty and the low level of competency among parents in the interests of their children – that something needed to be done. With the help of Save the Children and a French organization, we started to work on re-opening kindergartens, renovating their kitchens, restoring electricity and water, putting in doors and windows. There was nothing left almost. Once we did this, they started working with children and we started working with parents. It was a huge learning experience for me.

Her first grant to work directly with children with disabilities and their parents came from OSI Tajikistan and the Open Society Foundations' Mental Health Initiative (MHI)[13] in 2002. The grant was entitled "Consultative – Educational Family Center for Parents with Disabled Children" and was based in *Zdoroviye's* office space in Dushanbe. Venera Mirzoevna then participated in a study trip to Kazakhstan with others in civil society and government. Part of this trip included a visit to the Center

[13] The Mental Health Initiative was called the Mental Disabilities Assistance Program at this time.

"Kenes" which provides day programs for children with intellectual and complex disabilities. Venera characterized it as much more advanced than anything available in Tajikistan and a model for her work. She emphasized that she was the first to offer such services outside a residential institution and that it was accomplished without large amounts of funding – only small grants from OSI Tajikistan:

> We studied the principles – the way [they] worked [in Kazakhstan] so that parents would drop off their children in the morning and pick them up in the evening. There it was like a kindergarten, but they had grant funding. We did not have anything except some small grants from the Soros Foundation. People thought that I was crazy. Why is she working so hard? I bought toys and gave them to the kids so that they would be happy. People thought I was crazy, but ok. Then the Presidential Administration became interested in our work through social sector reform and they asked me (*поручили*) to conduct research in addition to our practical work on the situation for children with disabilities. We did this research and showed all of the minuses and few advantages, if you look from the point of view of reform. If you look from the Soviet vantage point, then everything had stayed as it was. I said that we need to work differently. We should respect these families, children should stay in their families and receive education there. Families should feel the support of local communities. We need to develop laws, services, financing mechanisms, and specialists – everything has to be done differently. We turned in that report and everyone was thrown off balance (*ошарашенный*) because it was such a huge amount of work.

Venera Mirzoevna takes great pains to discuss the importance of empowering parents but also alludes to the need for bridging social capital with allies if any changes are to come about within the system. She is also not shy about underlining the role that she played in building these social capital networks. Whether exaggerated or not, it is clear that this is where the founding mothers of IRODA, the APDC and Rushdii Inklusiia first met. Like others working in the region (Florian, 2011), she spoke at length about the barrier presented by defectologists whom she characterizes as intelligent professionals who are nonetheless stubbornly committed to old ways of doing things with scant results to show for their efforts:

> They were not idiots. They understood, but they did not want to work in new ways. We had a battle. And parents did not receive the level of quality services [that they needed] from these specialists because they worked in the old ways with the old programs. [Basically,] I see your defect and I am going to work with your defect. I told them that if they worked differently, if

> they looked for the interests of the child and worked based on his needs, it would be a completely different program and you would help him. You should support him. You have spent 20, 30, 40 years working [as a defectologist in a special institution] and can you say that you really have helped a single child? They answered, what can we do with them? I said, listen, you can change the quality of life for that child and that family. It's a huge difference. When they understood [what I wanted from them], they resisted me a great deal.

Between 2002 and 2006, *Zdoroviye* continued to operate a day program for children with disabilities, developing cooperation with a local kindergarten and attracting funds from UNICEF as well as continuing grants from OSI Tajikistan. Mothers would often accompany their children and work with them. They would meet there and talk to each other, learning and gaining confidence. Whether their empowerment was a direct goal of Venera Mirzoevna's work or an unintended consequence is unclear and somewhat contested by the mothers themselves. Venera Miroevna explains:

> The parents were on my side. I told them that I dreamed that they would get stronger and unite into associations so that they would be in charge themselves. I told them that they could do advocacy and attract resources, and then they could invite the specialists they respected to work. It's the same principle as requesting a place for your child in a respected teacher's class. I pushed them forward but they just did not unite.

It is unclear whether Venera Mirzoevna decided that parents should come together in associations because she truly believed this would benefit them, because she needed allies in her quest to keep children out of institutions, or because OSI Tajikistan suggested through its funding priorities that support to parents was important. All of these factors probably influenced events. Nonetheless, it is clear that this is the setting where the mothers who went on to found IRODA, SiDa, Rusdhii Inkliusia and the Association of Parents of Children with Disabilities met and explored what would work or not in support of their children.

This is confirmed in interviews with the original members of these groups, often with a mixture of gratitude and reticence to recount what has become a strained relationship with *Zdoroviye* and at times, amongst themselves. Lola Nasriddinova, one of the mothers involved with IRODA from

the early days spoke eloquently about her difficulty in reaching an assessment of autism for her son and in organizing services for him as part of the impetus for coming together:

> How it came into our heads to start something? When my child was diagnosed with autism he was 2.5 years old. Not one doctor could provide support to him, so we went from speech therapist to psychologist but each relationship would last only a few days until the specialist would apologize and admit that he had no idea how to work with my son. He is too complicated.

This story is typical of families affected by autism spectrum disorders, particularly before IRODA began offering services. Lola was very grateful for the opportunity for her son to have a spot in a kindergarten and for the networks that *Zdoroviye* provided. One of these contacts facilitated her study abroad in a program focused on including children with disabilities in education and the community for several months – a knowledge base that served as the methodological cornerstone of IRODA.

However, it is not surprising that relationships became strained. At the same time that she supports the idea of empowered parents coming together, Venera Mirzoevna also struggles with relinquishing power herself and demonstrates some beliefs about what might be possible for women from different social classes and with different levels of education to achieve. Regardless of Lola's characterization of her own motivations, Venera asserts her right to identify leaders and attributes her success in finally convincing the mothers to unite in 2006 to having identified a mother with higher education:

> In 2006 – four years later- I got the parents to look at things differently [by continuing to push them]. I also finally found a parent with education because most of the time poor women with little education came to us with their children, and they hoped for a cure. They looked at the medical aspect and thought that if they had come to us, we should cure the child so that he would be like everyone else. That was their thinking, so I struggled with them, to change their world view. I explained that you cannot remake a child physically or mentally, but your quality of life can change. You can adapt and then more positive things will happen. Let's do that together. You should unite and share information amongst yourselves. Then I did a survey… to figure out why they wouldn't unite. And it turns out, when I got the questionnaires back,

> women in Asia who suffer from domestic violence, when men are in charge of the family and she listens to him in everything - does not have her own opinion. Soviet women were more progressive. Soviet Tajik women could stand on their opinions. But those who live in mountainous or remote regions – they do everything as men tell them to do. Even if she has a different opinion. So I saw, when they wrote the answer that I don't believe in those clubs (*кружки*). If my husband tells me to go to the doctor or go to a teacher, we are going to do everything he says. If it doesn't work out, then we are going to raise a scandal and punish [the specialist].

There are layers of perceived difference and goals in this statement. In some ways, Venera Mirzoevna's characterization of the type of women who can be socially or politically active mirrors the profile of an active parent constructed from Harris (2004) and Katsui's (2005) research in the theoretical framework for this dissertation. Poverty, lack of education, the presence of men (Harris, 2004), and community standing are all important factors in the profile of an active mother of a disabled child. In the statement above, a woman fitting this profile is recast as Soviet – a category where Venera Mirzoevna would certainly place herself as well as a potentially divisive definition in a newly independent Tajikistan.

She says that, "we wanted to do it differently so that specialists would work in partnership with parents. Parents should also have an equal voice and equal rights. Then everything will work as it should." However, she also appears unwilling to take this advice to heart herself when the mother in question does not agree with her understanding of disability or lives within a more traditional family structure where the individual parent may not be as powerful an ally as the family unit as a whole. It is also possible that Venera Mirzoevna as a 'Soviet woman' was less able to establish a relationship of trust with a mother from a more traditional family. In choosing to push forward 'active mothers' with a background similar to her own, she may also inadvertently set up this cultural divide among member associations of the Coalition that seems to break down along urban – rural lines with the urban associations led by highly educated, professional women. This demographic is much less prevalent in the smaller and more rural associations. Venera Mirzoevna's disdain for women in more traditional

families is certainly reflected in her discussions of the reasons for supporting groups of progressive parents:

> We had very poor parents who had no education at all. They did not know how to feed their children, how to care for them. Most important, how to put it, traditions very much held them back. For example, tightly swaddling babies and using the *gahvora* (traditional cradle). Things like that. Some ideas about feeding, that after feeding they shake the baby and throw him up in the air. I said they would scramble his brains. Especially a child who already has some sort of defect. I said that there are some moments that will help you reach a mutual understanding with your child, a bond. Many did not have that bond, and we see this still today. I am ashamed to say, and they were ashamed to admit that they did not know they needed to tell stories or sing lullabies and to play with their babies if you want them to develop. From birth through three years old, babies develop through play.
>
> Many parents, even now when I ask, say that they don't play with their babies. They feed them and swaddle them so that they don't cry. I ask what they do instead. They say I have a mother-in-law and so I have a lot of housework. I ask them if they want something normal to grow from that child. If so, they must bring them up. You see, there are these tradition rules that prevent parents. But those mothers who have higher education, now there are women who have two or three degrees, of course they invest in their children huge amounts of love, opportunities, and of course money. I like to work with those mothers. Much better than those who don't know anything. They don't know which specialists to seek out, where to go or what to do. They don't know that they must repeat lessons at home with their child and that they need to work with him.

Despite decrying the conduct of defectologists as experts, Venera Mirzoevna behaves in much the same way, dismissing some parents as ill-informed and ineffective. She simply does this from a different vantage point than the defectologists. Her frustration with parents who will not unite and work for their children is expressed in ways similar to other professionals or experts who are frustrated with parents who can or will not follow their recommendations. She portrays herself as being embattled by defectologists from one side and recalcitrant parents afraid to take risks or stand up for themselves from the other:

> From the beginning of the idea of a parent association, that active mother was nervous. She said she had never done anything like that before. I said, listen, you have been with me for four years. Whatever you need, I will help you. She asked who she should work with because

> she was only one person, so I said that one and that one. There are three of you. It will work out. You make friends with each other. Together with my encouragement and the example of my success, she moved forward. It worked out.

The story of creating IRODA highlights the tensions inherent in the founding histories of the associations. To ask Venera Mirzoevna is to hear that Lola Nasriddinova was a reluctant leader who ultimately came around to her way of thinking and returned to the fold after a tumultuous departure:

> Lola, she also fought with me. She said, my son has autism, and I told her, you know, the best program for children with autism was developed by parents. Did you know that? It's because you know your child better than any specialist. We can just create the conditions for some sort of organization, whether it is private or public, but you should help your children. She was so cross with me. She left for India, but when she came back she asked forgiveness saying that before she had not understood. I told her to get out of here and go work. That's how it was with her.

Lola has a different interpretation of events, recalling that Venera was unable or unwilling to help her maintain a kindergarten placement for her son after a staffing change at the preschool. However, she remains grateful for the support that she initially received from *Zdorovïye* – a theme the emerged in interviews with other founding mothers of the associations in Dushanbe who remain grateful for the initial support but no longer work with Venera Mirzoevna. This is a sharp contrast to the warm relationship between the parents in Khujand and Sabohat Akimovna from Rangikamon. The ability to cut ties with Venera also indicates confidence and sufficient organizational effectiveness to survive and develop independently.

Empowerment and social capital from different vantage points

However, the contacts that the mothers made with each other and the new things that they learned were important for them in both finding common cause and understanding their differences. Lola explains:

> In addition to working with our children, we also talked with each other about our children and about things that were happening in the country. Our children had different diagnoses so

> some issues united us but there were also questions that related specifically to each of our children and their disabilities.

The timing of the creation of IRODA corresponds to the timeline that Venera Mirzoevna shared, but the circumstances are characterized differently by the founding mothers. Rather than focusing on Venera's identification of them as leaders, they identify the moment when the kindergarten where their children had been studying denied them the opportunity to continue as a catalyst for moving forward. Venera and her NGO were not always able to protect the parents from the vicissitudes of other organizations. For example, when the leadership of the kindergarten where several of the founding mothers had sent their children changed, some were told that their children could no longer attend because they were too difficult. Ill feeling at Venera Mirzoevna's inability to speak up on their behalf persists almost ten years later, underlining the depth of the original relationship of trust between Venera and Lola Nasriddinova, director of IRODA. Lola recounts:

> When we went to *Zdoroviye*, I met with five other mothers and asked Orr International [in 2008] if they had a specialist who could work with children with autism, so we started going to them once a week as well. There was a specialist in musical therapy, Pamela, and she worked very well with our children and also talked to parents about what autism is and brought news from the rest of the world. With the children she worked once a week. That continued for about 4 months. We got that letter [from the kindergarten] in May and in June Orr International offered me the opportunity to study in India…. At Orr International, I met Rachel, who was the coordinator of their disability project, and she offered me the chance to go to India because she knew that I spoke English. She saw that we were working not just with our own children but that we had created a small group of parents. I agreed to go. I went for a 3-month course on Community Initiatives in Inclusion in Mumbai. When I returned, my life had turned around 180 degrees because I had seen so many new things, like early intervention. We were in a center called Adapt – abled and disabled all together. We studied all kinds of disability, rehabilitation, inclusive education, work with schools and kindergartens.

At this point, the center of gravity for some of the mothers coming together, particularly those who would later found IRODA and SiDa, shifted from *Zdoroviye* to Kishti, a day center for children started as a project under the Association of Disabled Women "Ishtirok" with international funding. Lola Nasriddinova, founder of IRODA talks about her path:

> I started working at Kishti as the deputy manager. It was also very useful experience for me because it was the first center in Tajikistan that was doing anything in the field of early intervention and deinstitutionalization. We were working with children from orphanages and children's homes as well as children living in families. It was very good experience but after working for a year and a half I realized that, while I liked working with other families and helping them, my own son was left out. Nothing was developing for autism in Tajikistan. The children who were coming to Kishti had all kinds of disabilities by then – cerebral palsy, Down Syndrome, hydrocephaly, cleft palate, but not autism. I talked with Rachel and told her that I had found a 6-month course in India. I told her that I would continue working when I returned but I needed to learn how to work with children with autism. I can't help my own child and neither can specialists. The program [in India] was called Mother Child Program. It was organized by a parent organization called Sapantras. They had opened a center for children with autism. My son went to classes at the center and I went to classes in Sapantras, the parent organization. It was hard for my family to pay for this course of study. We had to sell an apartment. It was really hard because we had to live with my mother, but it was really necessary both for my son to attend classes and for me. Even though I was also a parent with a child with autism, we still had to pay for everything – for his classes and mine, and when an international expert came, we had to pay a conference fee. I wanted to learn so much but it was expensive.

Lola and other parents participating in interviews have spoken eloquently about the loneliness of autism. Children with autism do not have any disability that is outwardly visible, so their behaviors are interpreted as poor discipline or even mental illness. In this context, the importance of support from her mother and husband also emerged as themes in several interviews. Other mothers have also remarked on the importance of family support; however, this usually takes the form of allowing attendance at workshops, taking their child to the doctor. Selling an apartment – one of the single biggest forms of savings – in order to facilitate Lola's desire to learn how to support her son speaks to her significant powers of persuasion and the depth of her commitment.

As the leader of the organization, Lola speaks about her thirst for knowledge and information balanced against the expense of obtaining it. In the beginning raising funds meant the need to work together with others, including mothers of children with various needs, and to incubate within existing organizations. As Lola's narrative below relates, this can lead to conflict over resources:

> The organization that had received the grant, Ishtirok, would not let us register. They said that we were welcome to have an initiative group and hold trainings and activities, but did not give us permission to register a new organization. Their position was that we had written the proposal from their organization and so the project should be completed within their organization. It was a very complicated situation because we understood that we needed to register an organization. The problem of autism was real and we needed a separate organization.
>
> However, we also understood that we couldn't do anything if we left Ishtirok because the project would close. We agreed that we would complete the project within Ishtiork but as soon as the project was finished, we would register. They agreed but when the project was completed, again they did not allow us to register. We understood that we needed to separate and leave our space at Kishti or stay there but not register. We had a big meeting with the Soros Foundation, Ishtirok, us [the mothers], and even Caritas joined because at that time Caritas really wanted to support us to develop services for children. We persuaded the leadership of Ishtirok that we needed to register an organization. It was hard. There were conflicts. We separated and registered.

Thus, IRODA was not initially conceived as a parent association. It was supported by Caritas and OSI Tajikistan more as a parent-led organization to provide services for children. It has become a parent association through the accumulation of parents who desperately want to learn, like the pediatrician providing early intervention services who recognized that the mothers at IRODA could work more effectively with her son than she could despite her medical degree, as well as forays into national advocacy on behalf of parents.

The relationship between IRODA and Ishtirok seems to have normalized over time. Istirok's deputy chair participated in the May Forum by invitation with other DPOs. The groups recognize the value of partnerships among organizations, especially for advocacy. They may still view each other as competitors for funds, but also seem to respect the boundaries of constituency with IRODA supporting anyone affected by autism and Ishtirok hewing closely to the rights of girls and women with disabilities. The excerpt below from the Ishtirok representative's presentation at the May 6, 2015 Forum of the Coalition gives insight both into the potential for competition and the desire for cooperation:

I want to greet you again and tell you how important it is what you do as parent organizations. In our time, we did not have organizations that worked for our parents or for us. We started in 2004, thinking that we needed a group to defend the interests of women with disabilities. As you know, women can have specific problems, which are not usually discussed because of our mentality so they stay on the margins. In 2005 we began our activities as an affiliate of the League of Disabled People of Tajikistan, and in 2009 we registered as an independent organization - Ishtirok. Our main goals are providing equal opportunities to PWDS, to create an inclusive society without barriers, and to stop children from being placed in special institutions like Children's Homes. This is very close to the goals of the Coalition of parent associations. Our methods are also similar because we are all civil society organizations.

We understand that independent life and the right to choose mean that you can decide where and how to live, where to study, where to work, and to choose your own profession. We have talked about the many barriers and challenges on this path. However, uniting together is an important step that will give good results. We talked about the importance of inclusive education. We also think that this, as I said, in our time there were no centers where they worked with children with disabilities. I went to a regular school and in Soviet times, of course, it is because of my parents that I did not go to a special boarding school but stayed in a regular school. I am very glad that parent organizations are supporting the Concept on Inclusive Education, so that children should go to regular school, study together, grow up in their families, and grow up with their peers without disabilities instead of being isolated in special schools.

We are a women's organization and so one of our directions is work with children. We have a center for early intervention, Kishti, many of you know it, where children can go for early intervention programs. Our work with women and girls with disabilities is mostly educational in character. Unfortunately, women and girls with disabilities in remote regions do not receive information about elementary things. We provide training on legal literacy and skills. In the past few years at the initiative of girls coming to our organization, we have started English courses and courses on Internet literacy. In 2014-15, we have also given training in sign language for girls with hearing problems. We also work in the sphere of reproductive rights, what we call women's problems, so that women with disabilities can speak openly about this.

Often we have to ask for help to access public places. Transportation and infrastructure can be made accessible. Like the name of the film, *The Impossible is Possible*, there is a great deal that can be done if we want. We are open for cooperation to make sure that our society respects the rights of everyone and is accessible. What we want is not impossible or supernatural, after all. Be active! (Presentation, Sanovbar Raupova, May 2015, 33-51-106)

This last call to arms is meant to support the members of the Coalition as well as to impress on them the importance of critical awareness in their advocacy. It is not enough to advocate for access because legislation provides for it. They should advocate for access because it is a right being denied by a society that oppresses through discrimination and apathy.

Empowering organization or a victim of success?

Programs and services at IRODA have also evolved since these early days. At first IRODA was located in a small apartment and offered only individual services for mothers and children together with the goal of helping the mother learn to work with her child at home. Although not specialists, and certainly not portrayed in those terms, the staff at IRODA understood that they alone could not provide the necessary frequency and intensity of services for all the children who would need them because of limited space, time, and access to specialists. Training mothers as they went was a necessary compromise. Later, they moved to a larger space in a rented home and were able to offer services for children without the direct participation of family members. This has continued in their current space in School #72.

While providing a more recognizably professional level of services for children in classroom or classroom-like settings is an accomplishment marked with pride by the founding mothers of IRODA, this also has given rise to a new set of tensions. Lola Nasriddinova echoes her colleagues when she describes the notable difference in the ways that parents who have come later to IRODA view the organization.

> We feel that a barrier between staff and parents exists. We worry about this. We also worry that when parents come to us, they sometimes do not truly understand that we are parents, too. They come to us for ready programs. We asked one of our experts why this has happened when we are the same parents as before. We shared so many difficulties. Now the mothers who come to us come as clients. We are supposed to provide them everything. The expert said that when you started, you didn't have anything and that united you. Now you can offer

> something and those parents who come, many of them do not value it. They think that there is a center, there is a specialist, and I bring my child. What else am I supposed to do? Some of them also pay. If they pay, they don't think that they should do anything else. That is a big problem. (Lola Nasriddinova)

The services that IRODA can now offer have become so professional that they are no longer recognized as parent-provided, sparking important questions about the sustainability of the organization. "Lola works so hard. How much longer can she do this?" was a common refrain in conversations. It was also evident in interviews with the 'new generation' of parents that they valued the services for their children but did not see themselves in the same light as the rest of the staff. In some cases, this is justified because of hard-earned professional qualifications. One of the early intervention practitioners is a pediatrician as well as the mother of two boys with autism. However, she admits to becoming a staff member of IRODA because she saw that the staff was able to work with her older son more effectively than she could. Other staff who work with children came to IRODA with no professional qualification related to children at all and have earned certifications while working there, often with financial and or educational support from IRODA.

There are also structural indicators of IRODA's growing professionalism. They have a board with diverse expertise that can be leveraged to contribute to the organization in different ways, including raising funds. In addition to applying for grants from international donors, IRODA has set up a Global Giving page and discussed several avenues to pursue philanthropy from local businesses at the staff meetings I observed. It is also clear that the group is working well together. There was active and attentive participation from all staff members during meetings, and suggestions for solving problems were productive and creative, including the idea to create a simple database of parents' skills so that IRODA can call on them to volunteer or be more involved with specific requests.

SiDa is not quite in the same situation. They are operating on a smaller level with services provided in a small apartment provided by one of their members. However, they are thinking actively

about following IRODA's example and setting up shop within a school. They also have a slightly different challenge with the parents who come to them. The depression brought on by the cruelty of the original diagnosis of Down Syndrome is debilitating for both mothers and fathers, especially when the father has decided that he will stand by his wife and keep his family together. Much more support is needed to help these families navigate the system of assessment and pensions as well as psychological support to confront the stigma of having a child with a disability because families may be facing pressure to institutionalize or hide their child. Although parents of children with autism may be offered institutionalization as an option, it is not so consistently presented as a first choice, and there is no realistic way to hide a child who is already 2-3 years old as though he never existed.

During one of the focus groups, the mothers from SiDa elaborate on the stigma attached to Down Syndrome, identified at birth and associated with intellectual disability, and what they have tried to do to combat it:

> We have made short films, where parents have agreed, and showed them at the film festival so that they could show off their success. We have started collecting different types of information. We wanted to talk to this family, but neither parent would agree to give us an interview. An aunt of this girl spoke to us, although they are very … doctors, cardiologist, advanced (*продвинутые*) people. But they stay on this border. They can't say that they have given birth to such a child.
>
> They are afraid that they will lose their place in society if they say that they have such a child. That's way it is very important, in my opinion, to start from birth. If the child is identified [as having Down Syndrome] at birth, exactly at that moment we have to start working with the family. The most important moment, the decisive moment for that child is in the maternity hospital. What our mothers have experienced in the maternity hospital, they are still upset about it. I don't think that anyone but our mothers can understand it. Not every mother can be strong enough for everything they tell her. You leave the maternity hospital feeling like it is the end of the world and there is nothing that you can do. It is the worst moment.

The purpose of SiDa is first and foremost to provide support for parents and families when they learn that a child has Down Syndrome. Although acquainted with the mothers who were working with

Venera Mirzoeva and who went on to create the APDC and IRODA, Zamira describes her path in different terms, underlying the additional stigma faced by parents of children with intellectual disabilities from birth and early recognition that this set Zamira and her constituents apart from the other mothers. One of the founding mothers of SiDa recounts during a focus group:

> I had this idea for a long time, almost from the moment of my child's birth. I had so many questions about how to help my child and naturally there was nowhere to turn for answers, unfortunately. Even the people who were around me at the time, mothers in the same circumstances as me, didn't know what to do and just talked about how terrible it was [to have a child with Down Syndrome]. Then when my child was older, we had specific needs for education, for schooling. I understand that I did not do everything perfectly, but I did what I could. I wanted to find people who could provide consultations, to set something up. Why at that moment, I don't know. People told me I should put my child in an institution. For me that was the end. When I told my husband he said over my dead body. That was the best thing to say, but at the moment I was at my wit's end and thought that at the institution, at least someone will work with her, specialists, there will be something. I worked with her as I could. I also met the director of Special Olympics. I went to a conference [in 2007] and then my child competed in gymnastics.
>
> I met people and began corresponding with them. The idea that we should found something here in 2010. I met Zarina by chance in the Soros [Foundation]. There was a program to send parents to exchange experience. I went to Kyrgyzstan and then to Macedonia for exchanges. Then I met Zarina again at an event and we decided to start something. I had already started gathering the documents and had been to the Ministry of Justice [to learn about registration]. Then from 2011 we filed papers for registration and wrote a project to Soros as a parent organization so that we could offer consultations. In the beginning, there was more enthusiasm than professionalism.

This support can take different forms, and began with a great deal of legwork to find families of children with Down Syndrome, sometimes even approaching people on the street. One of SiDa's most active members explains the process:

> As soon as we started working, I would find mothers in the street. For example, walking in the underpass. Some were scared. I calmed them down and started registering children in our database. Then I was interested in how many children [with Down Syndrome] there were. I went to the Ministry of Health [and Social Protection of the Population] to learn if there were any such statistics, if anyone recorded Down Syndrome at the birth of a child. They said no.

> So we took the number of births each year and calculated a percentage of them. This isn't very precise, but it gives a general idea. (Nasiba, mother)

Sometimes the inquiries they receive show the depth of negative attitudes toward children with Down Syndrome. During my research a family from Kabadian contacted SiDa for help placing their child in an institution because that was what they thought was meant by support to parents of children with Down Syndrome. Two mothers in the focus group continue:

> That man from Kabadian, when a mother tells her son that he doesn't need that child instead of helping him, can you imagine how hard that is? When our family from Kabadian came, remember, they said that their child would never be able to walk. We asked who told them this. The doctors. How can they say this? Children with Down Syndrome can walk. They [doctors] are idiots. They don't know anything. Plus that poor father was worked over by his mother – the mother in law who said that they must come back without the baby. Whatever they do, they have to leave it in Dushanbe. You know, we talked to them so much. I asked Nasiba to work with them and she brought them here. There were four or five of them – aunts and uncles and a nephew with the parents. You can't imagine what a beautiful baby. She had a temperature of 39, maybe an infection from home. The mother is clearly afraid to give the baby to anyone, knowing why they came.
>
> We talked to them for hours, nothing worked. I told them that you will write your child into the institution in two minutes but if you change your mind, it could be complicated. The husband said he didn't care, as though someone had made him a zombie. I saw how the mother cried when she gave up the baby. The doctor also said that she couldn't take the baby with that fever. She had to be sent to the infectious diseases ward of the hospital. We can't keep her here [in the orphanage] even an hour. They asked the family, what if something happens and she dies? Will you come get her and bury her? They said yes. In less than a week, he calls me [saying] that he wants to take back the baby. It seems that the mother had a nervous breakdown and refused to see her husband. She said she didn't want to see him until he brought the baby back. Now the mother is in the hospital with the baby. I told him that now things don't depend on us. They depend on the director of the orphanage, whether they have filed your refusal of parental rights. If not, then they can tear them up. At orphanages, sometimes they hold the papers back for a few months in case families change their minds.

The sympathy from SiDa members, their confident refutation of the misinformation provided by doctors, and the positive examples of their own children with Down Syndrome may have given this mother the confidence to play the only card she had – complete refusal to continue seeing her

husband. Her husband's accession to her demand that her baby be returned is an indication of his decision to support her. He would have been within his rights to send her back to her birth family or simply divorce her.

SiDa has also continued to work hard to reach as many families as possible, both to offer support and to build the association. The founding mothers talk about how they began SiDa during a focus group:

> When we started, I want to add, we were just three. We wanted to find more families and so we held a public event near the Opera and Ballet Theater dedicated to the International Down Syndrome Day with our first 20 families. The families we got together, there were the people we knew. But Zamira [the current director of SiDa] also went to the polyclinic and to *Zdoroviye* to ask for lists of people with children with Down Syndrome. There were about 16 on the list and we began calling them. Some we found, some had left or couldn't be found. The people on the list whom we found came [to the event]. And then one of our mothers, M, she was also going to Kishti and knew that there were mothers with children with Down Syndrome. She sent them to us. I also remember that Sabohat [Hakimzoda] from the APDC sent people to us. Through our connections and friends, we found those first people who participated.
>
> [During the public event] people stopped in the street and asked questions when they saw us. Our volunteers were very active. If a car stopped, they would run up and give them a brochure to read. Some people returned and offered help. Truthfully, not what we needed, but the fact that they wanted to help … Good intentions, not enough knowledge.
>
> Then we opened our first center for support of families with [a grant from OSF] and then we applied to the Finnish organization Ablis and started to work actively. Within that project, we found our most active mama, who helped us find space. Within the framework of that project, we organized our first training for parents on the law, on their rights. We were also able to invite Down Syndrome International to the training, also with help from OSF. Andrew and others organized our first training on early intervention for children with Down Syndrome. It was attended by parents and people from the Republican PMPC, the city PMPC and school teachers. We tried to build a small team for that three-day training. After that we had several meetings with those organizations and also started working together more closely with international organizations. So our base started to grow up to 120 parents.

This recounting of their first activities shows a mixture of internal and external definition for SiDa's activities, indicating some elements of collective action and some elements of pragmatic interactions

with donors who have their own agenda. The founding mothers have a clear interest in finding others who have children with Down Syndrome. This is their founding purpose and an important manifestation of collective action, implemented with creativity and tenacity. The mothers of SiDa also recognize the importance of bridging social capital in their decision to hold public events and to recognize good will even if the results are not yet what they want. Finally, they allude to the need to work within the agendas of their donors. Certainly, the people who attended their workshop on legal rights gained something from the program. However, it is impossible to know whether this topic would have been the first choice among the founding mothers and their snowballing membership. OSI Tajikistan places the theme of legal rights and children's rights in their public documents from this time period (Annual Report, 2009), so leading with legal rights was a sensible fundraising strategy.

Now SiDa is focused on raising funds to provide direct services to families, but also on advocacy and counseling that they would continue to pursue even without funds because these activities cost only time and dedication. Although they do not offer the same level and quality of services as IRODA, the founding mothers of SiDa are also increasingly seen as professional service providers, counselors, and family mediators with services that evolve as their members' children grow up. For example, they are also looking for funding to start a dry-cleaning operation that would provide revenue and also help children gain employment skills and have begun a relationship with School #92 to open a resource center similar to IRODA's at School #72.

This pragmatic approach characterizes the rest of their work as well. The vestiges of the Soviet systems in health and social welfare as well as the network of special schools and orphanages are present but exist just enough to create bureaucratic hurdles and to collect funds from parents, but not to provide real services.

> We started working with the PMPC with the doctors, because this the organization that should be responsible for early identification. They haven't been very helpful but what they have done is make sure that the geneticist from Maternity Hospital #1 when she makes a diagnosis, she also gives our contact information, contact information for SiDa so that people can come here. For us that is important. We can't change her relationship to people, but at least she sends people here so that we can help them.

This system must be navigated before any state benefits, like a stipend for disability, can be collected. These services are confusing, sometimes in competition with each other, and often have unclear jurisdictional authority. This discussion also shows some elements of critical awareness in its understanding of the relationship between existing context, the mother hearing her child's assessment, and a pragmatic approach to changing what they can.

Throughout my research and relationship with these associations, assessment of disability in both policy and process is a particular sore point. At the May 2015 Coalition Forum, the room was silent except for the sound of pens uncapping when an official from the Ministry of Health and Social Protection offered that the association directors could call him with questions about assessment after a long and contentious airing of grievances.

The founding members of SiDa complain that Down Syndrome - not hearing loss or cardiac health or cognitive development - but Down Syndrome itself must be re-assessed and certified every two years, despite its permanence. Similarly cruel and counterproductive, the psychological hospital where the national PMPC refers parents, requires a 20-day hospital stay for observation and treatment to confirm an assessment of autism, although parents can make an informal payment of 400 TJS to obtain the necessary document without the hospital stay.

In this environment, both IRODA's and SiDa's leadership plans to work within the existing system but also to push its boundaries in new directions, demonstrating an understanding of structural discrimination and political context that indicates some level of critical awareness. For

example, SiDa is currently working with the Republican Center for Pediatrics to update the hospital reporting form to include Down Syndrome in addition to its potential consequences, some of which may be difficult to assess at birth. The group has already achieved an informal agreement with maternity hospitals in Dushanbe to refer families whose children are believed to have Down Syndrome. A change in the reporting form used nationally would allow for official statistics that would further facilitate development and advocacy for services. IRODA is working to have autism re-classified from a form of childhood schizophrenia to a developmental disability so that confinement to psychiatric hospitals and prescriptions of sedatives and anti-psychotic medication will no longer be an accepted 'treatment' protocol for children with autism (Lapham, forthcoming).

The strength and specificity of their advocacy agendas are likely to make both organizations successful in continuing to shift national policy forward as long as the country remains stable. The founding mothers of both IRODA and SiDa see themselves as leaders in the national Coalition with the mission of supporting the social model of disability and raising critical awareness among the parent groups who define their rights within the current system, which is heavily influenced by the medical model. The commitment of the founding mothers and those working at both IRODA and SiDa to professional development and professionalization of the services they deliver was evident throughout my research. The real challenge for both of these organizations will be to continue the spiral of empowerment for mothers who are joining them now. The tension between being a professional service provider and working as a collective of parents supporting each other with everyone contributing is acutely visible in these two associations, indicating strong collective action among the founding mothers but not necessarily among the newcomers.

Conclusions and common themes

The next chapter returns to the original research questions of the study to explore how the associations

described in these three case studies evolved and how the findings across all of the interviews and focus groups respond to them. There are also common themes that emerge from these cases beyond the specific frame of the original research questions. These include the shift from developing activities by families and for families to activities that reach out to the wider community, the ways that the associations understand themselves as organizations and members of a national Coalition, and the common quest for more and better information about how to support their children. These are explored in depth in Chapter 5.

Chapter 5 : Conclusions on empowerment and collective action

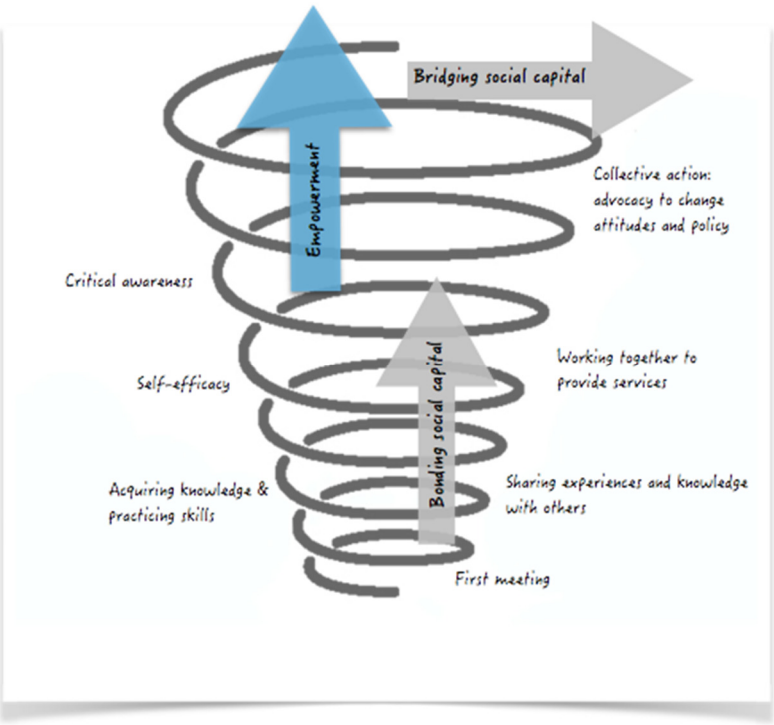
The case studies in the preceding chapter provide a picture of the similarities and differences among parent groups in different parts of Tajikistan. This chapter follows the structure of the empowerment spiral developed in Chapter 2 to provide a comparison across the cases, pulling out the common themes among them to respond to the research questions posed at the beginning of the study:

1. Under what circumstances do mothers of children with disabilities in Tajikistan decide to engage in collective action to support their children?
    a. How do the connections between the mothers evolve over time in the different geographical and organizational settings of the three cases?
    b. From the perspective of mothers of children with disabilities, what type of experiences empower them to take collective action?
2. What types of initiatives, in particular in education, are emerging from the parent groups in the three cases?
    c. When and how do they emerge? To what extent are they internally or externally driven and supported?
    d. From the perspective of mothers of children with disabilities, how do these initiatives affect their situation within their extended families and/or communities?

The second research question remained essentially unchanged. However, the first research question evolved as I developed the study because it presupposes elements of the empowerment model without naming them specifically. An exploration of social capital development is embedded in the first sub-question. The second sub-question collapses the personal journey from learning and confidence to self-efficacy and critical awareness into an exploration of lived experiences. This chapter pulls apart the elements of the empowerment model within the research questions and compares the

commonalities and differences between the members of different associations.

The tables that follow throughout this chapter summarize responses across the entire sample of interviews relevant to the stages of empowerment developed in the literature review and theoretical model in Chapter 2. In addition to tabulating responses to direct questions during the interviews, this chapter also includes an exploration of trends in responses that research participants offered when asked less structured questions about significant moments or series of events in their experience of having a child with a disability or as clarification to probing or follow-up questions. Some of these responses indicate areas for future research beyond the scope of this study.



This spiral describes the process of empowerment in three sections. In the bottom section, individuals gain knowledge and practice new skills, increasing feelings of self-efficacy, and then gaining the confidence to act and to reach out to others, extending the bonding social capital of common experience. In the middle of the spiral, members of the group begin to gain critical awareness by understanding that the stigma, discrimination, and a lack of power they face are embedded in the social, cultural, and political contexts they inhabit rather than inherent in themselves or their children as individuals. Subsequently, the process repeats until the connections among these newly empowered individuals are sufficiently strong to transfer the process of empowerment to the group as a whole. For the group,

the spiral continues to build and widen as activism and collective action to change attitudes and norms in the dominant population begin to have an effect, creating bridging social capital with allies, sometimes in their own families and in the general population.

Beginnings of empowerment: Knowledge, confidence, and self-efficacy

The trajectory of learning about a child's disability, understanding the family's rights and the services available, and developing feelings of confidence were similar across all three case studies but differed among research participants based on the cause and timing of a disability's appearance with significantly greater stigma experienced by those who gave birth to children with disabilities and mothers of children with intellectual or developmental disabilities.

Table 5.1: Learning about disability

When learned of disability	
At birth	16
Infancy	15
Toddler or older child	23
Acquired disability	5

Table 5.1 provides a summary of the timing of an assessment of disability among research participants responding to this question. The group is evenly divided between those who learned of their child's disability in infancy or at birth and those whose children were assessed later. Mothers of children who acquired disabilities through illness or accidents are the minority in this sample, but they make an interesting group for further research. It is difficult to draw conclusions from so small a sample, but the women in this category who spoke to me were quite comfortable discussing what had happened with their children. Their emotions ranged from gratitude for any help that they had received to outrage at those perceived responsible. For example, a woman in Khujand whose child's injury was the fault of the electric company was very happy to have received a one-room apartment as compensation.

Another mother from Bokhtar whose child contracted polio after having been vaccinated was

incensed with the idea that her child had been given a counterfeit or spoiled dose of vaccine – a misfortune that could be the result of corruption or poor management at any point in the supply chain, but which this mother places squarely at the feet of the local clinic. The women in this group of the sample who could blame others or outside events for their child's disability showed the greatest ease in discussing their children's disabilities.

Mothers whose children were identified as having a disability at birth reported the most significant distress, discrimination, and poor treatment. Mothers of children with Down Syndrome are the largest part of this sample. One mother in Dushanbe recalls a typical experience learning that her newborn daughter had Down Syndrome:

> When my daughter was born, the neonatologist came to me and said that she has Down Syndrome and then she left. And that's it. You have no idea what they have said, what's happening. I called my husband to come and get me and the baby. I didn't want to stay there anymore. I had already had two children, so I could compare. With the first two, they would bring the baby to you every five minutes to feed or change or do something. With this one, nothing (*изгой*), no one even comes in to ask a question or pays any attention. When my husband came, they said that they couldn't discharge me because the geneticist should come and give a conclusive diagnosis. We argued and decided to stay until she could come. My husband had to go get her [in our car] because she doesn't come on her own. She looked at my daughter and said she was very sorry but "your daughter really does have Down Syndrome." She didn't look me in the eyes, and after she said that she left.
>
> I was sitting there thinking what is so bad about that? Is it an infection that she is going to give everyone and it will kill us? So, my husband took her [the geneticist] back to her office and in that process, when he returned, I didn't recognize him. I could see that something was going on inside him that he wouldn't tell me. … I couldn't understand and kept questioning him. Finally, he said when he was taking her back to Maternity Hospital #1, after those 15 minutes, he was thinking that it really was the end of the world. She was asking why we would want such a baby. We were still young, we could have another. "You understand, she will spoil your whole life," [she said]. He still won't tell me everything she said. When he was telling me this, it was the first time that I had ever seen my husband cry in all the years we had lived together. Despite everything, I am so lucky that his family and my family really support us. It was never in his thoughts that we would put her in an orphanage, and I never thought that he would leave me, although this happens often in our circumstances.

This woman's experience, which was mirrored many times over across all three case studies, shows a lack of empathy and a lack of professional development in terms of knowledge of disability from healthcare providers – in particular, the doctor who is the making the assessment. It also underlines another recurring theme – the importance of family support.

By contrast, families who learned of their child's disability later in childhood had a different experience. This is especially true for parents of children with autism who delivered babies assumed to be typically developing. They struggled through the healthcare system to learn why their children were not developing typically when the characteristics of ASD began to become apparent around 12-18 months of age. For some parents, this process took years, although research participants noted a marked improvement among healthcare providers in Dushanbe over time in recognizing ASD and making referrals to IRODA. Although the mothers of IRODA and SiDa offer the clearest picture of the differences between delivery-room and later assessment of disability, their stories are consistent across all three case studies for experiences based on the timing of disability assessment.

Often difficult and heartbreaking, these are two different struggles with some similar feelings of powerlessness and alienation. Mothers in both groups typically experienced joy and celebration from their families upon learning that they were pregnant. For the mothers of children with Down Syndrome, this joy was often shattered in the delivery room, while for parents of children with autism the process of shame and ostracism was much more gradual. Some mothers of children with disabilities identified at birth reported having thoughts of suicide. A member of SiDa in Dushanbe recounts her story:

> They told me the details of this diagnosis…I didn't know what Down Syndrome was…I didn't understand what caused it…I suffered with the question of why this happened. In our culture, in our traditions, the reason is that you have committed some kind of sin…I looked for where or how I might have sinned. As far as I knew, I had never offended anyone….That made me suffer for a long time. Why have I always done everything for everyone but God has punished

> me this way? All the time, I was having girls…We have a big family, and I wanted to have one boy at least, and then I had another girl and a disabled one at that…Why did this happen? Sometimes there were conversations between the families about me having three girls and no boys. I thought, what would happen this time? If they know that I have given birth to a daughter with Down Syndrome, they will point their fingers at me…Then I thought about what would happen to my daughters. They love their father. What if our family falls apart? I decided that I should throw myself and my daughter out the window so that the rest could be happy.

Feelings of alienation and powerlessness were experienced differently by parents of children with disabilities that became apparent later. Having bonded with their child and having had the experience of bringing home a 'healthy' child, they were initially much more empowered as individuals with little shame about consulting healthcare providers assuming that their child had a treatable illness. This would shift as they were sent from doctor to doctor with little rewards for their efforts, finally learning that their child had a disability rather than an illness. A mother from IRODA recalls:

> When he was born, he was like any other child but at a year and a half, he stopped speaking…I thought it would pass but it didn't. We went to a doctor – a neurologist – and he said that my son had suffered trauma during birth and might have inter-cranial hypertension (*cherepnoe davlenie*)…We went to a speech therapist, too, but no one said that he had autism. When he was 7…a special education teacher said that she suspected he had autism. I didn't know then what autism was, but then I started to read and look on the internet…I went to the psychiatric hospital, to a young doctor and told him that someone suggested my son had autism. He told me no, that was a lie. Children do not have autism. It can only be diagnosed at 18 years of age. So I thought, well, they must not know anything to have told me that my child has autism. I gave him the medications that the doctor recommended for 2-3 days. They made him much worse! It was terrible…He slept all the time. He couldn't open his eyes…Since then I have not given him any medicines – not those psychiatric or neurological medicines, only antibiotics or something if he gets sick.

Accepting that their child had a disability and making the decision to stay together as family, supporting and working with the child was the first step for each parent across the cases. Learning about their children's disability was a vital subsequent step in order to understand how to help. This was true across all three case studies, although the mothers in Bokhtar were the most constrained in their access to information about disability. Learning about their children's disability and how to

support their development was a powerful incentive to come together both for women as individual and for associations in forming the national Coalition.

Table 5.2: Experiences in healthcare

Experiences in healthcare	
Offered institutionalization	9
Offered euthanasia	3
Disability defined in hopeless terms	7
Difficulty identifying disability	16
Given misinformation	17
Unkind or discriminatory behavior of healthcare workers	4

As the examples above begin to indicate, accurate information often was very difficult to obtain. My interview protocols did not focus on experiences in the healthcare system, so the responses in the table above indicate information volunteered in response to questions about learning about their child's disability and ways to provide support. I counted each respondent only once whether they indicated one of the challenges listed in Table 5.2 once or several times during the interview. Most respondents who described a difficult path to identifying their child's disability had children with ASD, but a significant number also had children with cerebral palsy, indicating an area for further research to explore whether healthcare workers generally lack awareness of disability and developmental milestones.

The 56 responses tabulated above underline the difficulty of obtaining accurate information about supporting children with disabilities, and in some cases, the danger of trusting healthcare workers to respond with competence and compassion to the family. The most surprising responses are those where a medical professional suggested euthanasia of a newborn with a visible disability, believing this to be the most compassionate course of action. This theme emerged several times in

Khujand and once in Bokhtar.[14] Less surprising, the question of institutionalization loomed large over the entire study, although I was working with families who had consciously decided not to place their children in institutions. In their responses, institutionalization was portrayed as the only option for the family by the healthcare provider, as in the example of the newly married couple referred to SiDa as a support service to arrange an institutional placement – information so incorrect that it is antithetical to the organization's mission:

> [In Chapter 4, we told the story of] that man from Kabadian. When a mother tells her son that he doesn't need that child instead of helping him, can you imagine how hard that is? When our family from Kabadian came, remember, they said that their child would never be able to walk. We asked who told them this. The doctors. … They [doctors] are idiots. They don't know anything. Plus that poor father was worked over by his mother – the mother in law who said that they must come back without the baby. Whatever they do, they have to leave it in Dushanbe. You know, we talked to them so much. I asked Nasiba to work with them and she brought them here [to the association office]. … We talked to them for hours, nothing worked. I told them that you will write your child into the institution in two minutes but if you change your mind, it could be complicated. (Focus Group, SiDa)

In this context, it is disheartening but not surprising to note the number of responses indicating difficulty in obtaining an accurate assessment of a child's disability or outright misinformation from healthcare providers. Families with means traveled to Moscow or Tashkent, where they felt medical professionals were better-trained. Respondents also indicated turning to the internet for more accurate information, although this option was available mainly in the urban centers of Dushanbe and Khujand. Improving assessment protocols and the functioning of the clinics and PMPCs that provide this service is part of the platform of the national Coalition.

Thus, one of the motivations for membership in the association for many parents was the exchange of information about disability, quality of available services, legal rights and how to access

[14] I did not include references to the experiences of others or reporting of rumors about healthcare providers in the tally of women who were offered euthanasia for their children. I counted only those who related a direct personal experience.

them, and other ways to support their children's development. This is a common theme across all three cases studies. Members of each association express gratitude and relief that they have the opportunity to learn together. The associations have also grown to see provision of information, consultation, and learning programs as a key part of their mission with 21 of 31 Coalition members indicating that they provide workshops or seminars and 18 indicating that they provide information about disability. Learning to pursue information and gaining the connections and experience to sort the good from the bad meant that mothers could begin to trust themselves to act in the interests of their children – an unexpected benefit from participation in an association. A mother in Dushanbe talks about her path:

> I see changes in myself [since coming to the association]. Before I did not understand this disability. I was worried and it hurt me that my child was born this way, honestly. Coming here and seeing other mothers – we have the same problem. Talking to them has made it easier for me. I want to fight this disability. Now I want to move forward.

An important part of increasing self-efficacy for many research participants included gaining confidence in their children as well as themselves. A mother from Khujand shared her story:

> They [medical professionals] told me that cerebral palsy is an incurable disease. Instead of supporting me, they told me that with this diagnosis anything I did would be a waste of time. But I try to help my daughter. She is smart, and she is pretty. She just doesn't walk but she studies in first grade. She has some difficulties writing because she can't hold the pen but she understands everything.

Seeing progress in their children as a result of their actions and refusal to give up is motivating and it increases feelings of self-efficacy. As mothers learn how to support their children, they see their actions making a difference and gain confidence themselves. A member of the association in Khujand speaks about this poignantly:

> We learn a lot for ourselves, for our children. It becomes easier for us. When I sat at home with my child, I thought that the worst thing in the world was that I had this child [with a disability]. After I started coming here…I thank God that my child is much better. Even

> though he doesn't walk, I thought that maybe one day he would speak, that I would hear him pronounce the word 'mother.' And now he can speak.

There were stronger feelings of self-efficacy expressed among the founding mothers of the associations in Dushanbe and Khujand – perhaps as a result of the length of their participation, their role in setting up the associations, the personal resources they initially brought to raising a child with disabilities, or some combination of all of these. This newer association member expresses a more ambivalent assessment of self-efficacy, seeing her own actions as necessary and consequential but also expressing a degree of reliance on the association and the services it offers.

Bonding Social Capital

This sense of not being able to fully support their children alone continues in the discussion of the ways that the connections between the mothers evolve over time in the different geographical and organizational settings of the three cases. This discussion also addresses the center of the spiral pertaining to the establishment of connections with others and the development of social capital. Across all three cases studies, there was some shared sadness and also a sense of shame among parents that motivated them to seek each other out, although this was especially pronounced among those who delivered a child with a disability at birth. There was also a shared sense of a dysfunctional healthcare system among all the parents which was especially strong among those whose children were identified later in childhood as having a disability. In Dushanbe and Khujand, interviews conveyed the sense of reasonably functional healthcare system where competency deteriorated quickly in terms of knowledge and attitudes about disability. In Bobojon Gafurov, the rural areas around Khujand, and Bokhtar there was a sense of both incompetence around disability but also difficulty accessing basic services.

Table 5.3: Benefits of Association Membership

Benefits of membership in the association	
Shared experience - mutual understanding	49
Information sharing	22
Improved access to expertise	9
Provision of services	13
Material support (job, money, childcare)	6
Support registering for a disability pension	10
Celebrations or public events for children	14
No response / Preferred not to answer	27

When asked why it was important or beneficial to be part of a parent association, 49 research participants responded that talking to others who share the same experience contributed to their emotional wellbeing. Further, 31 participants responded that sharing information about available services and the quality of services provided by different professionals was an important factor motivating participation in the group. This is consistent with research about similar groups in other geographies (Bjarnason, 2010; Walmsley et al., 2017).

Table 5.4: Education level

Education Level	
Basic	1
Secondary	47
Prof. Secondary	9
University	24
No Education	3

The fact that so many women specifically mention the value of new knowledge and learning could be related to the high level of education within the sample. Level of education is also common across case studies with the vast majority of women having completed secondary school and many having continued to university. University completion was slightly skewed toward the urban areas of Dushanbe and Khujand, but was not exclusive to these locations. Although the association members are welcoming and inclusive of women with much lower levels of education, these were newer members who were not part of the leadership. However, high average levels of

education do not mean that all mothers came to the groups with the same types of challenges or the same resources available to overcome them. Women in this sample ranged from highly educated women with foreign university degrees to women who had never attended any formal schooling, from women earning international salaries to women living in dire poverty, dependent on humanitarian aid and their child's small disability pension.

While they all entered the group with some raw material for bonding social capital, my research question began to surface ways that social capital forms strengthen and become augmented within a process of empowerment, beginning to transcend social barriers of education, class, and income that would normally be quite rigid. Indeed, these differences were not erased across the associations, just as they have not been erased in parent movements elsewhere (Bertelli et al., 2009). For example, the orientation toward progressive concepts of disability and education level between the Khujand association and the association they supported in the more rural Bobojon Gafurov district mirrors divisions across all three case studies and within the Coalition more broadly.

However, there were two common elements across research sites that united these women more strongly than their differences divided them. Most obvious among these is the shared experience of having a child with a disability with the attendant sadness, guilt, and confusion this experience can cause. The second was being able to strategize or rest from the negative reactions within their families. All of the mothers interviewed specifically mentioned the value of knowing that they were not alone in having a child with a disability and that others shared the challenges they faced. Once they found each other, bonding social capital through shared experience began to form:

> We are like one family. I think we are developing well as an association. In the beginning, we were very small. There were only a few of us in Khujand but now everyone knows about us. We all support each other as much as we can. Every year we do a holiday at my home…All of us parents, in the association, we are all together in the same situation.

Another commonality across the women in this sample included having the support or backing of at least one immediate family member, which became particularly important in proportion to the resistance or negative reaction from other members of the household. A commitment to reaching out to others was especially strong among those whose path to the associations was long and difficult.

Family relationships: Negative reactions and support

Relationships within the family are significant as both a source of motivation to seek out connection with others through an association and for the resources that some of the strongly positive relationships bring to the group. All of the association directors interviewed report a strong relationship with their husbands (with the exception of Saodat whose husband remains absent). In the case studies in Dushanbe and Khujand, the strong relationship between the association directors and their husbands provided a significant resource. For example, Lola's husband sometimes attends staff meetings at IRODA and pitches in with fundraising efforts. He also has allowed the sale of the family apartment that funded her initial training in India.

Table 5.5: Negative family member reactions to child disability

Negative family reactions	
Mother- or Father-in-law	19
Husband	13
Extended family	8

However, for many research participants, the experience of having a child with a disability negatively affected their family relationships, most often with their husband or mother- and father-in-law, as shown in Table 5.5. Two mothers in Khujand provide examples:

> When he [my husband, the child's father] would come and look [at our child], he would ask why God had punished him in this way. And then he would come less often – at first every other day, then twice a week, then once or twice a month. Now we have not seen him in a year. He has a different family and I am here alone.
>
> My husband said that he didn't want this kind of child and refused to acknowledge her.

These quotations illustrate two common themes throughout: associating disability with sin or punishment from God and the father cutting off contact or refusing to acknowledge either the child himself or the presence of disability. In the case of women whose husbands divorce them after the birth of a child with disabilities, there is also a dire lack of social capital for both mother and child. A divorced woman usually must leave her husband's family, and there is no guarantee that her birth family will take her back. This has two consequences. First, the mother will need to find some means of survival that includes earning money. Much of her time will be devoted to meeting basic needs, leaving little time for her to devote to her child's education and upbringing.

Second, it has the potential to completely sever the relationship between the mother and child and the rest of the community. It leaves the pair outside the framework of social structures that normally support the upbringing of children in tight-knit Central Asian families, kinship structures, and communities. A husband leaving has the potential to be a devastating loss of social connection. In addition to the emotional stress of a divorce from someone she may have cared for, the economic burden of a child with a disability and the possibility of negative gossip discouraging any future marriage is very high. A young mother in Chkalovsk explains her husband's blame and how her family holds together:

> I have two sons and I live alone with them. I work one shift as a nurse in the hospital. My husband said, you have a child with a disability. It is your fault. You didn't take proper care. We divorced. Now he has another family also with two sons. He pays no attention to us. I do everything. My son goes to school and a teacher comes to our home twice a week. He studies well. He is good at everything, but he can't walk. He can't feed himself or go to the toilet by himself. I do everything for him…My parents help but they are not here everyday. When I have problems, like with money, they help me….I have good relationships with my brothers. They help me.

Table 5.6: Support provided by family members

Family support	
Own mother	17
Husband	16
Sibling	7
Other	11

The support of at least one family member, usually the husband or the woman's own mother, is a vital lifeline. As indicated in the quote above, a positive relationship with her birth family, even if they are not able to help, either financially or practically, all the time, is highly valued and important to the well-being of this single mother. In cases where the woman's own parents were supportive, the promise of a place to go in the event of her marriage dissolving or being asked to give up her child was characterized as very important. All of the women in the sample reported at least one relationship with a close family member who was supportive, even in situations where many other family members had extremely negative views of disability and were ashamed to have a child with a disability in the family. A mother in Bokhtar said:

> In our family, I am the only one with such a child. My father has supported us since her birth. When we lived all together [with my husband's family], I was always busy with my child and couldn't do housework because she was often sick. My father had an empty apartment. He went to my mother-in-law and asked her permission to give us this apartment. My mother-in-law was then convinced that our child really does need extra care and gave us permission to move.

This quote demonstrates the importance of intercession by a supportive family member, in this case, the woman's father, but it also indicates her ability to communicate what she has learned about having a child with a disability to her mother-in-law with clarity and persuasion and a root cause of underlying tension even when the mother is not directly blamed for the child's disability – the time demanded by a child with a disability pulls her away from the duties that she would normally fulfill in the extended family. In this case, the agreement that the mother could live separately with her husband and children is also an acknowledgement that she will not be expected to engage in the same level of household work as other daughters and daughters-in-law living with the extended family – an accommodation

related to family well-being freeing her from guilt or recrimination for contributing less to the family as she cares for her child.

In cases where the husband was the supportive figure, this can be seen as unusual and worthy of mention, especially when the husband pitches in with a commitment of his own time and labor in addition to providing moral or social support. One mother explains:

> My husband's relatives] do not have a relationship with us. They do not want to…My husband helps me, even with work. I am a groundskeeper (*дворник*) and he helps me.

In some cases, a husband's support evolves over time and then requires significant and continued assertiveness with his own parents or even defying them, which could be seen as extremely transgressive in Tajik culture. A member of the nascent parent association in Chkalovsk provides a portrait of these family dynamics:

> My son started having seizures at three years old. My husband only began to react to him well after the seizures. Before that, every disagreement, every fight would come back to that – that I should send him to an institution. My husband's parents – not so much his father but his mother – she was completely against my child. When I went to the doctor she said that if they found out he was like that – sick – then I should ask the doctor to take steps – to put him to sleep or something like that. When he was 9 months old, I went to the doctor and cried. I told him that they had told me this at home and that I would never do this, but explained that she [my mother-in-law] had given me this 'friendly' advice.
>
> Then when he [my son] started having seizures, my husband came to himself (*пришел в себе*) and said that no one has the right to end another's life or kill him. It seems that he can die at any time and only at that time. Then he told me to take him to the doctor. Before that, he would tell me not to go, not to spend money. Then after that he changed and now is completely behind our child. He lets me go to the doctor, attend seminars. Before he would not allow me. He yelled at me. [His] mother and father are still not over the moon about it, but before my husband was behind them. Now he speaks against them – tells them to leave his child alone, what difference does it make to you, etc. They have backed off a little, but all the same..
>
> My husband works at a factory, I also work and my son gets a pension – 100 TJS per month – which is not even enough to buy his Pampers. One day, my mother-in-law called me and said that while I was still young I should go to work in Russia and leave my son in a residential

> institution. When I returned, I could take him back. She said I should go there, work, send her money and she would visit him. However, his grandparents – my mother and father-in-law – they are fine. They have enough money and could help me a little. But no one has helped me. Through all this only my own parents have helped me, thank God. Otherwise…

This case is particularly extreme. It is the only interview where euthanasia of a child with a disability was suggested for an older baby by a family member rather than a medical professional immediately following delivery. However, the sustained nature of the mother-in-law's campaign is not particularly unusual. The husband in this scenario seems to have effectively ended talk of euthanasia but the mother-in-law has continued to try to separate the child from the family and increase their collective income. The reference to still being young was also a common theme in this research, usually alluding to the possibility to have more children. In this case, it may signal that the mother-in-law finds this attachment to a child with a disability to be a youthful folly that separation by working in Russia might weaken. The woman interviewed signaled disbelief of the offer to take the child back from the institution upon returning from Russia as genuine.

Although it was not possible to interview women who were not association members, it is clear that her husband's support is essential for her to attend seminars and participate in the activities of the association, which she says in the same way that she indicates her husband's support for anti-seizure medication. Obtaining permission, or in lucky cases, encouragement, to engage in association activities and dedicate time and resources to a child with a disability was also a common theme through this research, as women are not expected to take on independent projects or social activities without approval from the extended family (Harris, 2005).

Bridging social capital, collective action, and empowering organizations

Writing about the relationship between social capital within the family and children's educational outcomes, Coleman (1988) argues that:

> the social capital of the family is the relations between children and parents (and, when families include other members, relationships with them as well). That is, if the human capital possessed by parents is not complemented by social capital embodied in family relations, it is irrelevant to the child's educational growth that the parent has a great deal, or a small amount, of human capital (p. S110). The social capital that has value for a young person's development does not reside solely within the family. **It can be found outside as well in the community consisting of the social relationships that exist among parents, in the closure exhibited by this structure of relations, and in the parents' relations with the institutions of the community**. (p. S113, emphasis added)

As discussed in Chapter 2, this framing is useful within this research because it provides an anchor for the idea that conditions or norms that negatively affect the relationships, generating social capital within the extended family or within the community could have a profound effect on the opportunities open to the individual. In Tajikistan, the stigma associated with disability itself and with giving birth to a child with a disability threatens these relationships. This in turn results in decreased access to, or even complete isolation from, social capital for both mother and child even if the mother has high individual human capital.

No matter how well-educated or empowered as an individual, access to social capital is central to realizing the right to community participation. Through the process of empowerment within the associations participating in this research, the key to reversing this dynamic is by leveraging increased self-efficacy and bonding social capital developed within the new community of the parent association to form bridging social capital that brings mother and child back into the greater community. Respondents reported feelings of greater confidence and wellbeing when contrasting their state of mind before joining the association and when they were interviewed, as an association member in Khujand explains:

> You could almost say that I became a doctor because of this child. I work with her from morning to evening [using what I learned here]. Physical therapy, gymnastics – I did everything. At seven years old, my child started to walk. I saw so many pluses.

There is certainly some selection bias in these responses, as parents who felt no benefits from participating in the associations would feel no need to continue attending meetings. However, documentation and information gathered during interviews with the leadership of the associations support a low level of attrition from the associations, usually resulting from changed external circumstances, such as moving to another city or a significant family change, including the death or institutionalization of a child. Membership in a parent group thus becomes an important pathway to developing social capital built on common experiences and needs but also a pathway to bridging social capital and respect in the broader and professional communities.

As they become more confident and their social capital within the group becomes stronger, association members dedicate time and energy to reaching out to others who may be having similar experiences, expanding their networks of bonding social capital. They also begin to develop a reputation among professionals and others in the community based on the expertise they have acquired and the services they provide – the first step to developing bridging social capital. In Chkalovsk, a daughter association of the Khujand parent group, the association has a small room in the local pediatric hospital to make referrals easier. In Dushanbe, respondents from IRODA indicated that several polyclinics and the PMPC refer parents to them, just as some maternity hospitals will refer parents whose newborns show signs of Down Syndrome to SiDa. One of the founding mothers of IRODA proudly recounts:

> Now it is much better. Almost all doctors know and now small children, as young as two years old, come to us. They are referred to us so that we can confirm that they have autism and offer services. The PMPC also refers people to us. …Probably that is because of Lola and the other parents. We had so many seminars for doctors and universities. The last time we had a training workshop on how to do screening for autism, we had doctors from the regions. They now know how to do this as well as doctors from Dushanbe. Thanks to that and also we often have articles in the media and work with the Ministry of Health. They also know what autism is. Probably thanks to that, everyone knows. People already even know the name IRODA.

This success is due in no small part to the substantial expertise that the founding mothers of these associations have developed by seeking out learning opportunities, trial and error in the experience of working with their own children, and building alliances with sympathetic professionals. These women have become respected experts and leaders in their own right. They sit on government working groups, like the committee tasked with drafting the Concept on Inclusive Education. They have also found common cause and built alliances with other civil society movements, like the collaborative work in Khujand between the parent association and human rights NGOs or the close relationship between the Coalition of Parent Associations and DPOs evident at the May 2015 forum.

In their research on empowerment, Maton and Salem (1995) find that an empowering organization must have a strengths-based belief system focused beyond the self that inspires growth, a multifunctional and accessible opportunity role structure, a support system that provides a sense of community, and leadership that is inspiring, shared, and committed to both the group as a whole and to its members. Developing bridging social capital by bringing disability into public view is a common theme across the cases that gives every member a meaningful role to play just by walking down the street with her child. It is also a strategy that has demonstrated positive effects in other contexts, in particular the changes in attitudes about sexual identity in the West (Broockman & Kalla, 2016).

The process of developing bonding and bridging social capital is highly relevant to the types of initiatives that are emerging from the parent groups in the three cases and the extent to which they are internally or externally driven and supported. In some cases, the desire to help others who may be suffering alone and reach out to new potential members forms the basis for collective action. One of the members of the Khujand association describes their outreach activities:

> It's not that they [other parents] found us through the kindergarten [#26]. We grew out of the kindergarten and now everyone knows about us. Now they come to us before they go to the kindergarten. We have lots of campaigns, activities, holidays, and other events. We are on the

radio, we hand out leaflets at clinics. That's how people find us.

Rather than giving into social mores encouraging women to be ashamed of their children with disabilities, this group in Khujand is developing public events and using mass media to announce themselves and the support that they can offer. The relationship to the education system plays an interesting role in both the individual process of empowerment but also in raising awareness about disability and building bridging social capital with the wider community. Mothers also reported being able to take action that benefitted themselves and their children, like this mother in Bobojon Gafurov:

> I worked in a mainstream kindergarten so that they would take my daughter, and there with the other children she opened up a little. In that kindergarten, she learned to walk.

This mother is noting the benefits for her daughter being with children who do not have disabilities in a kindergarten setting, but she was also building an important bridge into the community by introducing other families to her daughter in an educational setting:

> You could even say that we find them [other mothers of children with disabilities] on the street. With [another mother] we saw a boy on the street in a wheelchair. We went up to his mother and introduced ourselves to her right there. Sometimes we find them through relatives or friends. Through neighbors. We ask around. I had a neighbor who was 21 and she never went out. Her mother wouldn't let her out; she didn't have a wheelchair. We went with the girls [from the association] and gave her a wheelchair. Now she and her mother go out. Sometimes they come to our events. If someone says that such a family has a child with a disability but they don't go out, like that – by rumors. Look, I have a child with a disability. If I come to visit the mother, I don't know how but I will find a common language with her because we both have a child with a disability. At the beginning, if she doesn't want to take the child out or is ashamed… we talk and understand each other.
>
> When there is someone near you who can turn to, it helps. It's like a club where you can come and share your problems. Mothers can share their experience with each other – who has grown up children and who has little ones. They change as they grow up. Like all children, they grow up. Thanks to this center, it is easier for mothers.

These connections evolve over time in the different settings of the three cases in similar ways. The founding mothers are all well-educated and relatively affluent, perhaps reflecting the biases of the

NGO-led projects that first brought them together. The profile of later members is much more diverse in education level and income.

Table 5.7: Joining an association

Method of joining the association	
Founding member	14
Word-of-mouth or referral	14
Outreach from the association	12
Sought after event or media story	2

The majority of the people interviewed in Bokhtar indicated that they had come to the association for the first time. While still valuable for the development of the cases and the discussion of disability in Tajikistan more generally, they cannot be considered association members. Table 5.7 tabulates only the 57 respondents from Dushanbe and Khujand because the majority of the people interviewed in Bokhtar had visited the association for the first time to speak with me and attend the workshop delivered by a healthcare worker from Kurgan-Teppe.

The activities that the parent associations organize with and for their members provides insight into the needs and gaps that they perceive as well as the skills many of the association leaders are developing. Table 5.8 presents the responses from the survey completed by parent association directors during the annual forum on May 6, 2015. (See Appendix 9 for a complete summary.)

Table 5.8: Programs organized by parent associations

Question	Response
Direct support to children: How many children are involved in each type of program?	• School preparation (18) • After-school tutoring (10) • Therapy (occupational / physical) (6) • Counseling (9) • Registering for pensions (19) • Enrolling in KG / school (0) • Other (0)

What materials and modules do you use for your programs?	Adapted international material (11) Concept on Inclusive Education (1) Official policy documents (2)
Parent Support	• Legal / Advocacy (21) • Counseling / Self-help (20) • Information (about disability) (18) • Workshops / Seminars (21) • Other (2)
Do you have programs on inclusive education? If so, which schools work with you and how many children attend?	Yes = 13 No = 7 No response = 11
Other programs	• Education (classes or group work w/ children) (11) • Advocacy / public information (10) • Campaigns (12) • Other (4)
What does your association do best? What is your most important activity?	• Our children can act as disability ambassadors: 1 • Our children know their rights: 1 • Working with other associations: 2 • Inclusive education: 9 • Support for families of CWD: 11 • Working with children directly: 2 • Raise awareness about disability: 6
Ideas for the future – what programs or areas of expertise would you like to develop?	• School preparation (23) • After-school tutoring (13) • Physical therapy (15) • Occupational therapy (10) • Legal / Advocacy (20) • Education (classes or group work w/ children) (17) • Public information / Media (18) • Counseling / Self-help (22) • Information (about disability) (19) • Other: (5) exchange experience with other groups in Central Asia (1); early intervention (1)

The profile of the mothers who join these groups changes somewhat over time. In Dushanbe and

Khujand, the founding members of the group are more likely to have higher or professional education than newer members. They are also more likely to remain married and characterize their husbands as supportive. The major difference between the founding and newer members of the associations, however, is in their view of the associations themselves. While the founding women view the associations as mutual support groups and have developed projects and services themselves for the benefit of their children, those who joined later did not experience a time when there was no structured parent association. As the associations become stronger and more professional organizations, capable of raising funds and providing services, newer mothers begin to view them as professional service providers rather than parent groups. The director of IRODA explains:

> We have some active mothers who are just members of the organization and have attended all the seminars. You can say that they have come out of depression for the time being, because depression can return at any time. But we feel, even though we are also mothers, that many look at us as service providers. They don't think about their contribution, what they could do for the organization. That is a big problem for us. At one time, we had a parent club where we just met informally and talked about the challenges of autism in the country without any formal seminar. It has fallen apart a bit because we started some new programs – Mellow Parenting, Mother and Child – and training. It was hard to also organize the parent club. There was one mother – not a staff member – who organized it. She was very active but she went to America for a time and this stopped [the parent club]. It's a big minus and we feel it. We discussed it at the last staff meeting. We also used to have lots of outings in the park, outside the city – but this has also stopped because we have so much work.

The sense that there is always more to do and fewer people who are willing or able to take on responsibility for organizing is palpable, especially among the associations in Dushanbe. The small group of associations around Khujand is still expanding and relies on their founding NGO "Rangikamon" for fundraising, so the situation is less acute. In Bokhtar, the three leaders of the association see themselves in the role of NGO professional first and parent or family member of a disabled child second. Although the reliance of parents on the NGO for services is most acute here and the group is the least cohesive as a parent association, the tension of newer and older members

did not come up during interviews.

Critical awareness

At first the collective action that the association members develop is for the direct benefit of themselves and their children. This includes organizing parties and events where their children can enjoy the same types of activities as children without disabilities (i.e. receiving presents from Father Christmas, dancing and eating treats for the Persian new year, etc.). The next step is often action to support others going through a similar experience of having a child with a disability, like training and coaching programs to help parents learn strategies for supporting their children, negotiating with their families, and identifying good healthcare workers and professionals. The mother from Bobojon Gafurov who took a job in a kindergarten to be near her child continues:

> I started to participate in seminars and hear how children with disabilities should join society. I saw with my own eyes that my daughter made so much progress when I put her in a regular kindergarten. I decided that I should create this kind of organization so that all children could have the possibility to study in society [in mainstream schools].

It is not a long journey from these types of collective action to articulating critical awareness. Many association members began this journey with an intuitive sense of the social context's role in the stigma and challenges associated with having a child with a disability. Association members from Khujand and Chkalovsk describe this eloquently:

> I understand that you can work with a child and put him in society, then society will have to accept him. But first his mother herself must believe that and accept him.
>
> M [the association chair] supports us in everything. They give the children candy and presents, and when I bring this home, he is really happy. Before I didn't want to show my child to anyone. When you go out into the street, everyone points. It made me feel bad that everyone was laughing at my child. You can't do that, but not everyone understands that.

In these examples, the women clearly recognize that social attitudes and behaviors will have the potential to create problems. However, they do not all necessarily understand this as oppression or as

something that could be subject to change. For example, the woman who considered suicide when her child with Down Syndrome was born is pleasantly surprised when her husband expresses support and stands with her against pressure from his own family because she understands that this is not a foregone conclusion in the social context where she lives.

Forms of collective action: Once empowered, what changes do they make?

This critical understanding comes later and only for some of the association members. Critical awareness is manifested in the ways that some of the groups, especially in Dushanbe, advocate for changes in policy demonstrating very clearly that they understand the relationship between political processes and their children's wellbeing in society. Participants in the May 6, 2015 forum of parent associations were quite outspoken about their needs and challenges with government structures. Several of the presentations from Coalition members and DPOs talked about the value of closer relationships between NGOs and government agencies, particularly at the local level, and stressed the need for further training, professional support and improved pre-service training for professionals in health and education.

Following the presentations from the panel of national government representatives, several participants raised questions about the process of identifying and registering children with disabilities, including the lack of sensitivity of professionals responsible for the process, mandatory and highly-medicalized re-certification of disability every two years, and corruption. When the representative from the Ministry of Health offered that participants could contact him directly whenever problems of this nature arise, the head of the parent association in Penjikent asked for his phone number, which was greeted by the sound of 50 pens uncapping. One of the disabilities most acutely affected by this problem is autism:

Autism Spectrum Disorder (ASD) is listed as childhood schizophrenia in the register of mental

> illnesses and will only be diagnosed after a lengthy assessment stay in a psychological hospital. This is a prospect most families find quite traumatic, which is also completely unnecessary to the assessment of ASD. IRODA, which began as an association of parents of children with autism, is currently working with the Ministry of Health and Social Protection of the Population to develop a clinical protocol on autism that would allow it to be included in the register of disabilities as a neurological condition. If IRODA is successful in advocating for this clinical protocol, it will mean that children with autism will have the right to neurological assessment with support from pediatricians and neurologists and would no longer be subject to the cruel and counterproductive treatments for childhood schizophrenia currently included in treatment protocols. In addition, autism would be included in the register of disabilities eligible for a state pension (Lapham, 2018).

Changing clinical protocols represents a significant policy change that would begin to reshape the ways that the systems of public health and social welfare interact with people with disabilities. At the time of this research, only IRODA, SiDa, and the Khujand parent association were actively pursuing this type of transformative change with goals that they have identified through the experiences of the founding mothers. The other associations in these case studies and, more broadly, in the Coalition have focused on making the existing system work more transparently and effectively.

However, critical awareness and collective action also manifest across these case studies in the idea of holding events not only for children's enjoyment but also so that people will see them. A member of IRODA discusses why this is so important:

> Concerts, and the film festival – parents and the community was informed. In general, a great deal of work has been done on public information. Before no one knew what autism was. Now if you say to someone in the city that your child has autism, they say, yes, we know what that is. We saw your film.

This shows an understanding that part of the challenge of having a child with a disability rests with social attitudes, which can and should be changed by building relationships within the broader community (Broockman & Kalla, 2016). In the case study set in Dushanbe, this manifests in the desire to change policies, continually using the limited space for civil society in Tajikistan to push toward greater inclusion and recognition of the rights of people with disabilities (Lapham, forthcoming). In

both Dushanbe and Khujand, critical awareness can also be felt in the relationships developed between the parent associations and professionals. The director of IRODA recounts:

> [We wanted] to see the strength of parents' voices through our collation, through this movement because before parents might have said something but were easily dismissed. Professionals, especially doctors, looked at us with skepticism. How can you parents teach us something? Now this has changed. They come happily to our seminars.

Whether by changing the system or trying to force the system that exists to function properly, members of these parent associations are beginning to see their actions in empowered, political terms. They are not to be dismissed. This discussion gives a sense of the empowerment spiral across the three case studies from the base toward the top.

Throughout all three research sites, parent groups have devoted significant time, energy, and resources to reaching out to new parents and holding events, both public and private, that give children with disabilities the opportunity to experience childhood like their peers. These have included New Year's parties where Father Christmas distributes presents, picnics and excursions in the park, talent shows, and other common activities of childhood developed at the outset for the enjoyment of children and families. Some of these activities are publicly visible and have taken on the additional goal of informing the general public about the people with disabilities in their society.

Financial support and the lack of it are common themes throughout this research. Some associations, like SiDa, try to provide material support for families when they can. Others, like the association in Khujand, have decided that distributing material support distracts from their mission and prefer to leave it other organizations. Some initiatives that the mothers themselves suggested during interviews focus on raising funds, either for the association or to support families in difficult financial circumstances. One of the mothers from Chkalovsk offers:

I would like an activity like an exhibition – parents could make something, what they know

> how to make and we could show them for sale. We could put the money into a fund for our children, for services.

There is another subset of activities that coalesce around education. In some cases, these are services that the association provides directly to children, like the early intervention program that IRODA offers. In other cases, these are seminars or workshops that help parents navigate the systems of education, health, and social welfare or teach them how to support their children at home. Two of the three cases studies highlight organizations developing resource centers in mainstream schools with the goal of integrating children with disabilities who have not previously attended school. Mothers also frequently mentioned the need for better education opportunities for their children. Some expressed this as a desire for more special schools, noting that mainstream schools are not always welcoming or accessible, like this mother in Bobojon Gafurov:

> I wish that there were more special schools…. I am not against regular schools, but I wish that everyone wouldn't look askance at her [my daughter].

Others were excited about supporting inclusion. For example, the mother from Bobojon Gafurov who had worked in a kindergarten so that they would accept her daughter said:

> When I started participating in seminars and learned all about children [with disabilities], that they should join society – and I saw this myself with my daughter when she went to a mainstream kindergarten and made so much progress. I decided that I should create such an organization so that all children would have the opportunity to study in society. In the region where we live there are many such children, so we decided to start a separate association [from the one in Khujand].

Two of the case studies place education quite centrally. Of the four parent-founded organizations in Dushanbe, three are located in schools. All have educational programs and support parents in seeking education placements for their children. In Bokhtar, one of the central projects of the association is setting up a resource center in a local school in hopes of integrating children with disabilities who have not previously attended school.

In all three cases, there was a delicate dance between the needs that parents defined and their desire to work together to address them, the need for financial and technical resources in tackling these challenges, and the missions and plans of local and international donors in Tajikistan. In Bokhtar, striking a workable balance has meant developing a unique organizational structure that can be marketed to donors operating in different thematic areas clustered around rural livelihoods and agriculture on one hand and social support, education, and disability on the other. In Khujand, the need to maintain a connection to donors has meant keeping a close relationship with the NGO that incubated the association so that the founding mothers can participate in projects to make ends meet.

In Dushanbe, the greater availability of resources has allowed for a more diversified strategy that includes writing grants and projects, partnering with local institutions like the schools described above, and cultivating wealthy members and corporate sponsors, like the businesswoman who built a private kindergarten to include children with Down Syndrome so that her own child would have access or reaching out to the Hyatt Hotel to host the Coalition's annual forum for free.

The balance of individual decisions, donor influence, and collective action shifts pragmatically over time and across the three case studies but ultimately comes back to way that a critical mass of the mothers involved define the needs of the parent community. For example, the development of school-based resource centers in Dushanbe and Bokhtar may be opportunistic to take advantage of the associations' capacity to attract support in the donor community that exists now, but the associations would not be able to move forward if there were not parents who wanted their children to be included in the mainstream school community.

Concluding thoughts

At the beginning of this study, I discussed the importance of civil society development in post-Soviet development and transition projects. Organizational form is also a common theme throughout the cases. In the field of international development, empowerment is often associated with institutionalized forms of participation through local government, civil society organizations or non-government organizations, small business cooperatives, or other structures where people might engage in collective action. The themes of formal registration, organizational independence, and incubation appear across all three cases. Organization structure and closeness with the founding or incubating organization differs significantly across these three cases.

There is some evidence that Venera Mirzoevna set expansionist goals for the work with parents from the beginning, viewing the original group from the NGO *Zdoroviye* in Dushanbe as her foot soldiers. This goal and its possible links to funding from international agencies may have worked with her own views on disability and womanhood to obscure the nuanced interests and ideas expressed by research participants in favor of a more universal focus on legal rights and income:

> I won a grant from the EU and we went to districts – Hissar, Kulob – and advanced that theme, which I think is very important. In the regions, they should know about the laws affecting families as well as crisis support programs. We worked with a network of rights-defending organizations, and we gave them addresses. Women, we have a lot of migrant laborers now – so we gave them addresses because the men leave their wives behind and do not send money. It destroys the family. So we gave them information – we worked with the legal aspect, with education and upbringing. I have about six mothers – one whose child had a complicated defect – who have become directors of local organizations.

In Khujand, it is also evident that Sabohat Akimovna from the NGO Rangikamon is central in raising funds to help develop parent groups in the far-flung districts of Soghd veloyat. In the end, expansion and independence come at a different pace and are highly dependent on interpersonal relationships and pragmatic concerns about access to resources.

At first glance, especially to a donor, many of these associations could appear project-driven and funding dependent. This may be true for some activities, but certainly not all. For example, the organization in Bokhtar still provides consultations to those who seek them out whether they have funds or not. The creativity of the organization in Bokhtar in navigating a complex funding environment also demonstrates a deep commitment to their mission, even if they cannot disclose it fully to all their donors. Thus, Jo Baker's (2010) recommendation that this parent group not be incubated too long within Furughi Marifat lest it stifle the voices of parents is an important caution to the organization but shows that the true relationship of the two is difficult to understand. Requiring Saodat to spin off to create a truly separate parent group would probably weaken both FM and the parent association – a calculation that is evident in their current structure.

In the other two cases, internal difficulties with leadership and power relations are certainly present to varying degrees in all of the associations, in Soghd and elsewhere, perhaps leading in part to the formation of new associations. This is easy to picture, in particular, for the association in Bobojon Gafurov where the director appears to be quite dominant. There is also an alarming amount of medical misinformation, in particular about cerebral palsy and questionable diagnoses like inter-cranial hypertension (*cherepnoe davlenie*) (notes, May 2015). Parent groups can share information about doctors and specialists, and parents can learn a very great deal to support their children. However, they cannot replace medical professionals. The future will depend on their ability to engage and secure training opportunities for competent and sympathetic medical professionals working in Tajikistan. Efforts in this direction are clearly visible in the case study in Bokhtar, in the co-location of the Chkalovsk parent group in a children's hospital, and in the policy advocacy agenda of the Dushanbe associations.

Perhaps the largest divide within the Coalition is the division between those who would change the system completely because they have subscribed fully to a social and political model of disability and those who understand disability through a version of the medical model tempered by an understanding of barriers and accommodations. This second group advocates implementing the provisions of the current system competently and transparently. Both of these groups acknowledge the importance of the other's mission and relate to each other with respect. However, it is unclear how long they will continue to find common cause working together closely.

The functioning of the existing system is certainly important for parents. In the survey of all the associations in the Coalition 21 report providing consultations to parents and 19 help with disability pensions or other aspects of the social services bureaucracy as part of their core activities. Ten mothers specifically identified help in navigating the social services or legal system as one of the benefits of membership in a parent association. However, this is not the only benefit of membership or the only need that motivates parents to take action.

Lola and Zamira, leaders in Dushanbe-based organizations, have noted that an exclusive focus on legal issues can also come at the expense of engaging with more contemporary understandings of disability and rehabilitative support designed using evidence produced in the past 20-30 years. This, in turn, leads to feelings of difference (or hierarchy) between associations in Dushanbe and Khujand and more remote regions as well as further tension among the associations in Dushanbe. The director of IRODA recounts:

> You know, most of them were formed from Sabohat [Hakimzoda's] organization because Sabohat worked on that [network] before the coalition. She worked on that in many regions, and they have a strong emphasis on the legal aspect, like Sabohat. On one hand, I am very happy about that because the legal aspect is very important, but on the other hand, for example, since they have less focus on methodology, like rehabilitation, they lag in this area. However, we understand that not every parent organization has specialist-parents like us.

> Therefore, unfortunately, what happens? They invite specialists who work using these outdated methods. That is upsetting. If they invite a physical therapist, for example, he works with out-of-date methods. It would be good if parents in the Coalition, if they were familiar with modern methods and lobbied for the use of modern methods with their children. So that they didn't demand free medicine or physical therapy that includes electrophoreses, massage – those methods that no one uses anymore. All the same, they have a very strong accent on the legal aspect. That is very good. However, their understanding of their children as having disabilities is a bit behind.

This difference is especially apparent in education programming where, within all case studies there is also a hierarchy of disability that places children with intellectual disabilities at the bottom as well as difficulty supporting parents whose children have complex disabilities or challenging behaviors, mostly because there is little available information or expertise to bring to bear in supporting them. Inviting international and other organizations into the Coalition has been suggested by some of the associations in Dushanbe as a way of mitigating this tension. Places where organizations like Caritas and Mission East have supported community-based rehabilitation (CBR) programs are characterized as better or more modern. This dynamic, regardless of the evidence about what works with children, is interesting for what it says about the relationship between respect and disagreement, empowerment and hierarchy within networks of social capital.

The future for these parent associations, individually and collectively as a Coalition, will depend on the ability of the founding mothers to mitigate these differences and to foster an ongoing process of empowerment among mothers that renews leadership within the associations. The challenges of balancing advocacy and movement building with service provision under the umbrella of collective action is not unique to Tajikistan (Christens & Speer, 2015). Nonetheless, it is an acute challenge for Tajikistan's parent associations both in finding common voice with each other and in continuing the empowerment spiral for new members. Lola expresses this idea eloquently:

> [We began]to see the strength of parents' voices through our coalition, through this movement because before, parents might have said something, but were easily dismissed. Now this has

> changed [but I am worried that we can go back]…. The question [of parents viewing us as service providers] is a very important question because that happens specifically with young mothers who either have just received their diagnosis or, whether she has the diagnosis for a long time or not, has complicated circumstances in her life. We have noticed this. We have some active mothers who are just members of the organization and have attended all the seminars. … But we feel, even though we are also mothers, that many look at us as service providers. They don't think about their contribution, what they could do for the organization. That is a big problem for us. At one time we had a parent club where we just met informally and talked about the challenges of autism in the country without any formal seminar. It has fallen apart a bit because we started some new [formal] programs – Mellow Parenting, Mother and Child – and training. It was hard to also organize the parent club. There was one mother – not a staff member – who organized it. She was very active but she went to America for a time and this stopped [the parent club]. It's a big minus and we feel it. We discussed it at the last staff meeting. We also used to have lots of outings in the park, outside the city – but this has also stopped because we have so much work.
>
> I can't do this [organizational work for events] and the others who did this before also have some complicated challenges in their families, so this has gone quiet for the moment but we feel that a barrier between staff and parents exists. We worry about this. We also worry that when parents come to us, they sometimes do not truly understand that we are parents, too. They come to us for ready programs. We shared so many difficulties. Now the mothers who come to us come as clients. We are supposed to provide them everything. They think that there is a center, there is a specialist, and I bring my child. What else am I supposed to do? Some of them also pay. If they pay, they don't think that they should do anything else. That is a big problem when we tell parents that we are also parents. It is hard for us and we need their support. [We tell them] even when you go to the polyclinic and say that your child has autism, or advocate for your pension, then you are advancing the ideas of the organization. Don't be silent. Don't be afraid.

The continuation of empowerment of parents of children with disabilities in the future depends on bridging the divides apparent within and among the associations. It also depends on their capacity to support their newest members in making the leap from gaining a sense of self-efficacy in raising a child with disabilities to critical awareness that places their challenges within a social and political context as a motivation for collective action.

Contributions to theory and research

Tajikistan is an under-researched geography with most of the academic research that does emerge focusing on political development and the legacy of the civil war. Research on education or other social services conducted or supported by international donors often assesses specific development challenges or evaluates specific programs or projects. There is very little rigorous research that focuses on the experience of individual people or communities in all the complexity of the context of their daily lives. This dissertation fills in these gaps by examining the relationship between empowerment and social capital formation among mothers of children with disabilities in Tajikistan as a result of their participation in parent associations. The three case studies developed in Chapter 4 build on the work of Colette Harris (2004) to provide a picture of womanhood and gendered resistance to entrenched social norms through the unique and specific experiences of mothers of children with disabilities. At the same time, the cases and the findings presented in Chapter 5 build on and expand Katsui's (2005, 2013) exploration of disability and disability-focused social movements in Central Asia.

Second, much of the existing research on social capital has emerged from the United States with a smaller literature from Europe. Very little academic research on social capital formation is conducted in developing countries or in the Persian cultural context to which Tajikistan belongs. This dissertation research extends the existing theoretical work on social capital to a developing country, namely Tajikistan, to offer an important perspective on how people seek and develop social capital under differing circumstances. This contextual extension of theory has the potential to be useful for further research in both the developed and developing world as populations shift through migration and immigration, and as developed countries' increasing economic inequality leads to some communities experiencing levels of deprivation similar to the poorest developing countries.

Additionally, the framework of empowerment is used frequently in both academic literature and the publications of international organizations. The concept has existed in the literature of disciplines ranging from education to women's studies since the 1970s. Psychologists discuss empowerment in terms of mastery and self-determination at the individual level, and the field of community psychology talks about fostering involvement, social conflict and social support (Hyung Hur, 2006). In the field of international development, empowerment is often associated with institutionalized forms of participation through local government, civil society organizations or non-government organizations, small business cooperatives, or other structures where people might engage in collective action (Narayan-Parker, 2002). This dissertation develops a framework based on the common elements across these fields (see Chapter 2), contributing to the literature on empowerment and extending a model begun during previous research in Tajikistan (Whitsel & Lapham, 2014). In addition to exploring the empowerment of individual women, this research explores the social capital developed between them and its relationship to continued or further empowerment and activism – a gap in current research noted by Christens (2012).

In addition to contributions to research, this dissertation has policy implications as well. The mothers in these associations are becoming increasingly well-organized and informed about the ways that policy changes come about. Paralleling similar movements in the United States and elsewhere, they are taking steps to make changes in national policy. For example, autism spectrum disorders are listed as childhood schizophrenia in the register of mental illnesses and will only be diagnosed after a lengthy assessment stay in a psychological hospital. This is a prospect most families find quite traumatic. IRODA is currently working with the Ministry of Health to develop a clinical protocol on autism that would allow it to be included in the register of disabilities as a neurological condition. If IRODA is successful in advocating for this clinical protocol, it will mean that children with autism will have the right to a neurological assessment with support from pediatricians and neurologists, and

would no longer be subject to the (cruel and counterproductive) treatments for childhood schizophrenia currently included in treatment protocols. Autism would be included in the register of disabilities eligible for a state pension (Lapham, 2018).

Association leaders are also beginning to take part in the international policy scene. For example, the founding mothers of IRODA and the association in Khujand have been on forefront of advocacy to sign the Convention on the Rights of Persons with Disabilities, which took place in March 2018. They have also contributed to the public discussion for the general comment to Article 24 of the Convention, which deals with education. This had tremendous signaling value for the associations at home by indicating that their members are internationally recognized experts. This firmly places the associations on a trajectory to change the existing system at the same time as they build it through the services that they provide to children and their families.

Finally, by amplifying the voice of a population that is often silenced or completely invisible in Tajikistan, I hope that his research project has further empowered participants by validating their experience as valuable and important. Through interviews, focus groups, and extended conversations, the mothers in each case have contributed to a unique understanding of the relationships between empowerment and social capital in Tajikistan. More often viewed as the recipients of charity, public services, or knowledge from professionals and international experts, the opportunity to see themselves as expert contributors by telling their own story is powerful as they continue to organize and press for change to policy, practices, and attitudes about disability in Tajikistan.

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Appendix 1: List of Abbreviations

ADB	Asian Development Bank
APDC	Association of Parents of Children with Disabilities
CBR	Community-Based Rehabilitation
CEECIS	Central and Eastern Europe and the Commonwealth of Independent States
CIS	Commonwealth of Independent States
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
EFA	Education for All
GPE	Global Partnership for Education
iNGO	International non-government organization
IQMSC	Integrated Questionnaire for the Measurement of Social Capital
IRODA	Association of Parents of Children with Autism
LSMS	Living Standards Measurement Survey
NEDS	National Education Development Strategy
NGO	non-government organization
OECD	Organisation for Economic Cooperation and Development
OSF	Open Society Foundations
OSI	Open Society Institute
PMPC	Psychological Medical Pedagogical Commission
SiDa	Association of Parents of Children with Down Syndrome
UNESCO	United Nations Education, Science and Culture Organization
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WB	World Bank

Appendix 2: Basic facts about Tajikistan

Political Map of the Republic of Tajikistan

Source: CIA World Factbook, accessed on 7/6/2014

Tajikistan is located in southeastern Central Asia. It is a small, landlocked country sharing borders with the Kyrgyz Republic to the north, Afghanistan to the south, Uzbekistan to the west and China to the east. More than 93% of the country is mountainous, and nearly three quarters of the population live in rural areas near river valleys boasting Tajikistan's small areas of arable land. It has a population of around 7 million people and is currently experiencing rapid population growth. The majority population is ethnically Tajik, with Uzbeks (15.3% in official figures but sometimes estimated as much as 25%) forming the largest ethnic minority. An estimated 90% of the population is Muslim. Tajik (part of the Persian language group) is the official state language, with Russian used as a prominent second language for government and business.

Tajikistan declared independence from the Soviet Union in 1991, but civil war among regional groups soon followed lasting until a cease-fire in 1997. It has the lowest GDP in Central Asia at US$2,300 per capita in 2013. The literacy rate in Tajikistan is estimated officially at 99.5%, but these figures are not consistent with the high dropout rate from primary education beginning as early as third grade, which (UNICEF, 2007) estimates at more than 7%. Statistics on general demographic indicators are available only through 2008 on the web site of the state statistical agency and the numbers of people with disabilities in Tajikistan are difficult to find. According to the most reliable figures obtained by international organizations and state agencies, in 2004, there were 17,693 children under the age of 16 registered with a disability (OECD, 2009, p. 213).

Appendix 3: Literature Review Sources and Tabulation of Themes

American Journal of Community Psychology

Citation	Year	Knowledge	Skills	Self-efficacy	Context process	Connect w/ others	social capital	critical awareness	Individual action	collective action	increase resources /	Measurement (ind)	Measurement (group)	Qualitative or action
———. "In Praise of Paradox: A Social Policy of Empowerment over Prevention." *American Journal of Community Psychology* 9, no. 1 (February 1981): 1–25. doi:10.1007/BF00896357.	1981													
Gruber, Judith, and Edison J. Trickett. "Can We Empower Others? The Paradox of Empowerment in the Governing of an Alternative Public School." *American Journal of Community Psychology* 15, no. 3 (June 1987): 353–71. doi:10.1007/BF00922703.	1987				1									
———. "Terms of Empowerment/exemplars of Prevention: Toward a Theory for Community Psychology." *American Journal of Community Psychology* 15, no. 2 (1987): 121–48.	1987	1		1	1	1				1				
Wolff, Thomas. "Community Psychology and Empowerment: An Activist's Insights." *American Journal of Community Psychology*, 1987. http://psycnet.apa.org/psycinfo/1988-24416-001.	1987				1			2	1		1			
Zimmerman, Marc A., and Julian Rappaport. "Citizen Participation, Perceived Control, and Psychological Empowerment." *American Journal of Community Psychology* 16, no. 5 (October 1988): 725–50. doi:10.1007/BF00930023.	1988													

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Florin, Paul, and Abraham Wandersman. "An Introduction to Citizen Participation, Voluntary Organizations, and Community Development: Insights for Empowerment through Research." *American Journal of Community Psychology* 18, no. 1 (1990): 41–54.	1990	1	1	1							1			1
Price, Richard H. "Wither Participation and Empowerment?" *American Journal of Community Psychology* 18, no. 1 (February 1990): 163–67. doi:10.1007/BF00922694.	1990							2						
———. "Taking Aim on Empowerment Research: On the Distinction between Individual and Psychological Conceptions." *American Journal of Community Psychology* 18, no. 1 (1990): 169–77.	1990		1	1	1				1	1				
Zimmerman, Marc A., Barbara A. Israel, Amy Schulz, and Barry Checkoway. "Further Explorations in Empowerment Theory: An Empirical Analysis of Psychological Empowerment." *American Journal of Community Psychology* 20, no. 6 (December 1992): 707–27. doi:10.1007/BF01312604.	1992		1	1	1			1	1			1		
Bond, Meg A., and Christopher B. Keys. "Empowerment, Diversity, and Collaboration: Promoting Synergy on Community Boards." *American Journal of Community Psychology* 21, no. 1 (1993): 37–57.	1993	1				1	2		1	1	1			1
Riger, Stephanie. "What's Wrong with Empowerment." *American Journal of Community Psychology* 21, no. 3 (1993): 279–92.	1993			1				2		1				
Fawcett, Stephen B., and Glen W. White. "A Contextual-Behavioral Model of Empowerment: Case Studies Involving People with Physical..." *American Journal of Community Psychology* 22, no. 4 (August 1994): 471.	1994													
Gibbs, Jewelle Taylor, and Diana Fuery. "Mental Health and Well-Being of Black Women: Toward Strategies of Empowerment." *American Journal of Community Psychology* 22, no. 4 (August 1994): 559–82. doi:10.1007/BF02506893.	1994													

Serrano-García, Irma, and Meg A. Bond. "Empowering the Silent Ranks: Introduction." *American Journal of Community Psychology* 22, no. 4 (1994): 433–45.	1994				1	1		2						
Silka, Linda, and Jahnvibol Tip. "Empowering the Silent Ranks: The Southeast Asian Experience." *American Journal of Community Psychology* 22, no. 4 (August 1994): 497.	1994													
Trickett, Edison J. "Human Diversity and Community Psychology: Where Ecology and Empowerment Meet." *American Journal of Community Psychology* 22, no. 4 (August 1994): 583–92. doi:10.1007/BF02506894.	1994													
Edelstein, Michael, and William K. Hallman. "Citizen Participation and Empowerment: The Case of Local..." *American Journal of Community Psychology* 23, no. 5 (October 1995): 657.	1995	1	1	2	1	1				1				1
Fawcett, Stephen B., Adrienne Paine-Andrews, Vincent T. Francisco, Jerry A. Schultz, Kimber P. Richter, Rhonda K. Lewis, Ella L. Williams, et al. "Using Empowerment Theory in Collaborative Partnerships for Community Health and Development." *American Journal of Community Psychology* 23, no. 5 (October 1995): 677–97. doi:10.1007/BF02506987.	1995	1	1		1	1		2		1				1
Kroeker, C.j. "Individual, Organizational, and Societal Empowerment: A..." *American Journal of Community Psychology* 23, no. 5 (October 1995): 749.	1995													1
Maton, Kenneth I., and Deborah A. Salem. "Organizational Characteristics of Empowering Community Settings: A Multiple Case Study Approach." *American Journal of Community Psychology* 23, no. 5 (1995): 631–56.	1995			2		1								1
McMillan, Brad, Paul Florin, John Stevenson, Ben Kerman, and Roger E. Mitchell. "Empowerment Praxis in Community Coalitions." *American Journal of Community Psychology* 23, no. 5 (1995): 699–727.	1995	1	1	1	1	1			1				1	
Perkins, Douglas D. "Speaking Truth to Power: Empowerment Ideology as Social..." *American Journal of Community Psychology* 23, no. 5 (October 1995): 765.	1995	1	1	1	1	1		2	1		1			

Perkins, Douglas D., and Marc A. Zimmerman. "Empowerment Theory, Research, and Application." *American Journal of Community Psychology* 23, no. 5 (1995): 569–79.	1995				1	1		2	1		1			
Rappaport, J. "Empowerment Meets Narrative: Listening to Stories And..." *American Journal of Community Psychology* 23, no. 5 (October 1995): 795.	1995				1	1			1	1	1			
Rich, Richard C., Michael Edelstein, William K. Hallman, and Abraham H. Wandersman. "Citizen Participation and Emprowerment: The Case of Local Environmental Hazards." *American Journal of Community Psychology* 23, no. 5 (October 1995): 657–76. doi:10.1007/BF02506986.	1995	1		1	1									1
Speer, Paul W., and Joseph Hughey. "Community Organizing: An Ecological Route to Empowerment..." *American Journal of Community Psychology* 23, no. 5 (October 1995): 729.	1995			1	1	1		1	1	1	1			
Spreitzer, Gretchen M. "An Empirical Test of a Comprehensive Model of Intrapersonal Empowerment in the Workplace." *American Journal of Community Psychology* 23, no. 5 (October 1995): 601–29. doi:10.1007/BF02506984.	1995	1		2								1		
Zimmerman, Marc A. "Psychological Empowerment: Issues and Illustrations." *American Journal of Community Psychology* 23, no. 5 (1995): 581–99.	1995	1	1	1	1	1		2	1	1				1
Saegert, Susan, and Gary Winkel. "Paths to Community Empowerment: Organizing at Home." *American Journal of Community Psychology* 24, no. 4 (August 1996): 517.	1996													
Foster-Fishman, Pennie G., and Christopher B. Keys. "The Person/Environment Dynamics of Employee Empowerment: An Organizational Culture Analysis." *American Journal of Community Psychology* 25, no. 3 (June 1997): 345–69. doi:10.1023/A:1024628711026.	1997													
Foster-Fishman, Pennie G., and Deborah A. Salem. "Empirical Support for the Critical Assumptions of Empowerment Theory." *American Journal of Community Psychology* 26, no. 4 (August 1998): 507.	1998			1	1		2		1		1			1

Sprague, Joey, and Jeanne Hayes. "Self-Determination and Empowerment: A Feminist Standpoint Analysis of Talk about Disability." *American Journal of Community Psychology* 28, no. 5 (October 2000): 671.	2000													
Angelique, Holly Lizotte, Thomas M. Reischl, and William S. Davidson II. "Promoting Political Empowerment: Evaluation of an Intervention With University Students." *American Journal of Community Psychology* 30, no. 6 (December 2002): 815.	2002													
Fetterman, David M. "2001 INVITED ADDRESS: Empowerment Evaluation: Building Communities of Practice and a Culture of Learning." *American Journal of Community Psychology* 30, no. 1 (February 2002): 89–102. doi:10.1023/A:1014324218388.	2002	1	1			1								1
Campbell, Rebecca, Heather Dorey, Monika Naegeli, Lori K. Grubstein, Kelly K. Bennett, Freya Bonter, Patricia K. Smith, Jessica Grzywacz, Patsy K. Baker, and William S. Davidson Ii. "An Empowerment Evaluation Model for Sexual Assault Programs: Empirical Evidence of Effectiveness." *American Journal of Community Psychology* 34, no. 3–4 (December 2004): 251–62. doi:10.1007/s10464-004-7418-0.	2004											1		
Peterson, N. Andrew, and Marc A. Zimmerman. "Beyond the Individual: Toward a Nomological Network of Organizational Empowerment." *American Journal of Community Psychology* 34, no. 1/2 (September 2004): 129–45.	2004			1	1		2	2	1		1			
Davidson, Heather, Scot Evans, Cynthia Ganote, Jorie Henrickson, Lynette Jacobs-Priebe, Diana L. Jones, Isaac Prilleltensky, and Manuel Riemer. "Power and Action in Critical Theory Across Disciplines: Implications for Critical Community Psychology." *American Journal of Community Psychology* 38, no. 1–2 (June 27, 2006): 35–49. doi:10.1007/s10464-006-9061-4.	2006							1	1					1

Peterson, N. Andrew, John B. Lowe, Joseph Hughey, Robert J. Reid, Marc A. Zimmerman, and Paul W. Speer. "Measuring the Intrapersonal Component of Psychological Empowerment: Confirmatory Factor Analysis of the Sociopolitical Control Scale." *American Journal of Community Psychology* 38, no. 3–4 (September 15, 2006): 287–97. doi:10.1007/s10464-006-9070-3.	2006		1	1		1			1			1		
Rivera, Héctor H., and Roland G. Tharp. "A Native American Community's Involvement and Empowerment to Guide Their Children's Development in the School Setting." *Journal of Community Psychology* 34, no. 4 (July 1, 2006): 435–51. doi:10.1002/jcop.20108.	2006												1	
Maton, Kenneth I. "Empowering Community Settings: Agents of Individual Development, Community Betterment, and Positive Social Change." *American Journal of Community Psychology* 41, no. 1–2 (2008): 4–21.	2008	1	1	1	1	1					1			
Bishop, Brian J., David A. Vicary, Alison L. Browne, and Neil Guard. "Public Policy, Participation and the Third Position: The Implication of Engaging Communities on Their Own Terms." *American Journal of Community Psychology* 43, no. 1/2 (March 2009): 111–21. doi:10.1007/s10464-008-9214-8.	2009							1	1	1				1
Bringle, Robert G., and Kathryn Steinberg. "Educating for Informed Community Involvement." *American Journal of Community Psychology* 46, no. 3–4 (September 25, 2010): 428–41. doi:10.1007/s10464-010-9340-y.	2010	1	1	1					1			1		
Dworski-Riggs, Deanne, and Regina Day Langhout. "Elucidating the Power in Empowerment and the Participation in Participatory Action Research: A Story About Research Team and Elementary School Change." *American Journal of Community Psychology* 45, no. 3–4 (March 16, 2010): 215–30. doi:10.1007/s10464-010-9306-0.	2010	1	1	2		1	1		1	1				1

Javdani, Shabnam, and Nicole E. Allen. "Councils as Empowering Contexts: Mobilizing the Front Line to Foster Systems Change in the Response to Intimate Partner Violence." *American Journal of Community Psychology* 48, no. 3–4 (November 23, 2010): 208–21. doi:10.1007/s10464-010-9382-1.	2010	1	1		1	1						1		
Kellett, Mary. "Small Shoes, Big Steps! Empowering Children as Active Researchers." *American Journal of Community Psychology* 46, no. 1/2 (September 2010): 195–203. doi:10.1007/s10464-010-9324-y.	2010													
Balcazar, Fabricio, Yolanda Suarez-Balcazar, Sandra Adames, Christopher Keys, Manuel García-Ramírez, and Virginia Paloma. "A Case Study of Liberation Among Latino Immigrant Families Who Have Children with Disabilities." *American Journal of Community Psychology* 49, no. 1/2 (March 2012): 283–93. doi:10.1007/s10464-011-9447-9.	2012	1	1	1		1		1	1	1				1
Christens, Brian D. "Toward Relational Empowerment." *American Journal of Community Psychology* 50, no. 1–2 (2012): 114–28.	2012		1	1	1	1		1	1					
Grabe, Shelly. "An Empirical Examination of Women's Empowerment and Transformative Change in the Context of International Development." *American Journal of Community Psychology* 49, no. 1/2 (March 2012): 233–45. doi:10.1007/s10464-011-9453-y.	2012			2	1		2	1			1			
Kegeles, Susan, Gregory Rebchook, Lance Pollack, David Huebner, Scott Tebbetts, John Hamiga, David Sweeney, and Benjamin Zovod. "An Intervention to Help Community-Based Organizations Implement an Evidence-Based HIV Prevention Intervention: The Mpowerment Project Technology Exchange System." *American Journal of Community Psychology* 49, no. 1/2 (March 2012): 182–98. doi:10.1007/s10464-011-9451-0.	2012													
Brodsky, Anne, and Lauren Cattaneo. "A Transconceptual Model of Empowerment and Resilience: Divergence, Convergence and Interactions in Kindred Community Concepts." *American Journal of Community Psychology* 52, no. 3/4 (December 2013): 333–46. doi:10.1007/s10464-013-9599-x.	2013	1	1	1	1				1					

Ozer, Emily, Sami Newlan, Laura Douglas, and Elizabeth Hubbard. "'Bounded' Empowerment: Analyzing Tensions in the Practice of Youth-Led Participatory Research in Urban Public Schools." *American Journal of Community Psychology* 52, no. 1/2 (September 2013): 13–26.	2013													
Speer, Paul, N. Peterson, Theresa Armstead, and Christopher Allen. "The Influence of Participation, Gender and Organizational Sense of Community on Psychological Empowerment: The Moderating Effects of Income." *American Journal of Community Psychology* 51, no. 1/2 (March 2013): 103–13. doi:10.1007/s10464-012-9547-1.	2013	1	1	1	1	1	2	1				1		
Cheryomukhin, Alexander, and N. Peterson. "Measuring Relational and Intrapersonal Empowerment: Testing Instrument Validity in a Former Soviet Country with a Secular Muslim Culture." *American Journal of Community Psychology* 53, no. 3/4 (June 2014): 382–93.	2014		1	1	1	1						1		
Christens, Brian, Paula Inzeo, and Victoria Faust. "Channeling Power Across Ecological Systems: Social Regularities in Community Organizing." *American Journal of Community Psychology* 53, no. 3/4 (June 2014): 419–31. doi:10.1007/s10464-013-9620-4.	2014													
Collins, Charles R., Jennifer Watling Neal, and Zachary P. Neal. "Transforming Individual Civic Engagement into Community Collective Efficacy: The Role of Bonding Social Capital." *American Journal of Community Psychology* 54, no. 3–4 (September 16, 2014): 328–36. doi:10.1007/s10464-014-9675-x.	2014						1		1	1			1	
Neal, Jennifer. "Exploring Empowerment in Settings: Mapping Distributions of Network Power." *American Journal of Community Psychology* 53, no. 3/4 (June 2014): 394–406.	2014													
Neal, Zachary. "A Network Perspective on the Processes of Empowered Organizations." *American Journal of Community Psychology* 53, no. 3/4 (June 2014): 407–18. doi:10.1007/s10464-013-9623-1.	2014													

Peterson, N. "Empowerment Theory: Clarifying the Nature of Higher-Order Multidimensional Constructs." *American Journal of Community Psychology* 53, no. 1/2 (March 2014): 96–108.	2014													
	Total	**19**	**20**	**30**	**24**	**21**	**12**	**26**	**22**	**13**	**11**	**8**	**3**	**14**
	Specific	19	20	20	24	21	2	8	22	13	11	8	3	14
	Related	0	0	5	0	0	5	9	0	0	0	0	0	0

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Citation	**Year**	**Knowledge**	**Skills**	**Self-efficacy**	**Context process**	**Connect w/ others**	**social capital**	**critical awareness**	**Individual action**	**collective action**	**increase resources**	**Measurement (ind)**	**Measurement (group)**	**Qualitative or action research**
Hoffman, Cecil. "Empowerment Movements and Mental Health: Locus of Control and Commitment to the United Farm Workers." *Journal of Community Psychology* 6, no. 3 (July 1, 1978): 216–21. doi:10.1002/1520-6629(197807)6:3<216::AID-JCOP2290060303>3.0.CO;2-Y.	1978					1			1			1		

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Levine, Oneida H., Paula J. Britton, Tammy C. James, Anita P. Jackson, Stevan E. Hobfoll, and Justin P. Lavin. "The Empowerment of Women: A Key to HIV Prevention." *Journal of Community Psychology* 21, no. 4 (October 1, 1993): 320–34. doi:10.1002/1520-6629(199310)21:4<320::AID-JCOP2290210408>3.0.CO;2-6.	1993			1	1	1								
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Prati, Gabriele, and Bruna Zani. "The Relationship between Psychological Empowerment and Organizational	2013			1	1		2					1		

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Total	**8**	**7**	**17**	**14**	**12**	**8**	**12**	**11**	**2**	**4**	**12**	**0**	**5**
Specific	8	7	15	14	12	0	6	11	2	4	12	0	5
Related	0	0	1	0	0	4	3	0	0	0	0	0	0

Appendix 4: Master List of Interviews and Documents

Place	Date	Number	Transcribed	Time	Event	Organization
Bokhtar	14-May	52-120	1-Jun	20.18	FG	Bokhtar
Dushanbe	1-May	12-41-168	3-May	68.13	FG	SIDA
Dushanbe	1-May	28-26-157	3-May	24.65	FG	SIDA
Dushanbe	1-May	54-40-174	3-May	20.88	FG	SIDA
Khorog	6-Jul	35-13-156		34.47	FG	
Khujand	19-May	23-39-148	22-Jun	65.07	FG	Khujand
Khujand	22-May	43-57-172	22-Jun	18.92	FG	Chkalovsk
Khujand	22-May	49-06-187	22-Jun	36.57	FG	Chkalovsk
Kulob	18-Jun	47-57-137	21-Jun	55	FG	Staff
Kulob	18-Jun	22-38-130	8-Jul	50.25	FG	Jamoat groups
Murghab	3-Jul	07-57-192		42.5	FG	
Dushanbe	6-May	05-35-115	7-May		Forum	MoES
Dushanbe	6-May	18-56-178			Forum	MoHSPP
Dushanbe	6-May	28-29-173	7-May		Forum	Forum
Dushanbe	6-May	31-22-128	8-May		Forum	IRODA
Dushanbe	6-May	40-54-117	8-May		Forum	Dushanbe
Dushanbe	6-May	56-38-163	8-May		Forum	Rushdi
Dushanbe	6-May	19-16-181	8-May		Forum	Imkoniyat
Dushanbe	6-May	33-51-106	8-May		Forum	Ishtirok
Khorog	6-May	07-31-194	8-May		Forum	Khorog
Khujand	6-May	22-05-115	7-May		Forum	Sarchasma
Kulob	6-May	47-27-178	8-May		Forum	Kulob
Bokhtar	14-May	45-06-146	1-Jun	30.12	Int	Bokhtar
Bokhtar	14-May	06-14-166	1-Jun	11.05	Int	Bokhtar
Bokhtar	14-May	17-36-104	1-Jun	13.83	Int	Bokhtar
Bokhtar	14-May	31-38-176	1-Jun	18.15	Int	Bokhtar
Bokhtar	14-May	50-43-167	1-Jun	13.83	Int	Bokhtar
Bokhtar	14-May	05-08-110	1-Jun	14.62	Int	Bokhtar
Bokhtar	14-May	20-58-140	1-Jun	11.72	Int	Bokhtar
Bokhtar	14-May	33-47-187	1-Jun	13.78	Int	Bokhtar
Bokhtar	14-May	47-59-120	1-Jun	40.18	Int	Bokhtar
Bokhtar	14-May	45-59-122	1-Jun	13.92	Int	Bokhtar
Bokhtar	15-May	16-12-158		0.00	Int	Bokhtar
Bokhtar	15-May	08-27-177	1-Jun	12.13	Int	Bokhtar
Bokhtar	15-May	29-13-185	1-Jun	11.90	Int	Bokhtar

Bokhtar	15-May	48-07-132	1-Jun	35.20	Int	Bokhtar
Bokhtar	15-May	02-33-137	1-Jun	14.50	Int	Bokhtar
Bokhtar	15-May	45-03-196	1-Jun	14.20	Int	Bokhtar
Bokhtar	15-May	17-16-126	1-Jun	10.33	Int	Bokhtar
Bokhtar	2-Jun	31-37-173	29-Jun	23.95	Int	Bokhtar
Bokhtar	2-Jun	58-51-146	28-Jun	15.33	Int	Bokhtar
Bokhtar	2-Jun	41-38-122	29-Jun	15.67	Int	Bokhtar
Bokhtar	2-Jun	58-46-151	21-Jun	22.35	Int	Bokhtar
Bokhtar	2-Jun	26-22-152	28-Jun	14.72	Int	Bokhtar
Dushanbe	25-Apr	40-23-158	25-Apr	23.10	Int	IRODA
Dushanbe	27-Apr	28-15-152	27-Apr	9.35	Int	IRODA
Dushanbe	27-Apr	39-45-142	28-Apr	9.28	Int	IRODA
Dushanbe	27-Apr	49-53-158	29-Apr	16.45	Int	IRODA
Dushanbe	27-Apr	15-41-152	29-Apr	10.07	Int	IRODA
Dushanbe	27-Apr	47-00-170	29-Apr	12.95	Int	IRODA
Dushanbe	27-Apr	16-40-181	29-Apr	6.32	Int	IRODA
Dushanbe	27-Apr	28-27-158	29-Apr	26.23	Int	IRODA
Dushanbe	27-Apr	00-53-104	29-Apr	19.75	Int	IRODA
Dushanbe	2-May	59-56-146	3-May	9.12	Int	IRODA
Dushanbe	7-May	21-07-174	8-May	39.6	Int	SIDA
Dushanbe	18-May	42-55-178		33.38	Int	AKF
Dushanbe	8-Jun	23-53-144	15-Jun	40.17	Int	IRODA
Dushanbe	8-Jun	53-31-197	24-Aug	22.1	Int	IRODA
Dushanbe	10-Jun	50-31-126	21-Jun	89.77	Int	Mission East
Dushanbe	10-Jun	11-52-196	16-Jun	24.6	Int	Caritas
Dushanbe	11-Jun	11-48-175	15-Jun	16.7	Int	IRODA
Dushanbe	11-Jun	34-37-134	15-Jun	31.07	Int	IRODA
Dushanbe	11-Jun	09-20-118	15-Jun	11.67	Int	IRODA
Dushanbe	12-Jun	15-01-167	15-Jun	23.07	Int	SIDA
Dushanbe	12-Jun	53-11-165	24-Aug	15.65	Int	SIDA
Dushanbe	12-Jun	40-04-185	15-Jun	12.38	Int	SIDA
Dushanbe	16-Jun	54-01-194	21-Jun	53.92	Int	Zdoroviye
Dushanbe	22-Jun	14-38-129	26-Jul	13.85	Int	SIDA
Dushanbe	22-Jun	39-28-193	25-Aug	37.3	Int	SIDA
Dushanbe	23-Jun	04-59-119		38.98	Int	Sabohat
Dushanbe	24-Jun	57-14-156	28-Jun	51.58	Int	Lola
Dushanbe	25-Jun	99-99-625	27-Jun	20.00	Int	SIDA
Dushanbe	25-Jun	01-29-145		43.58	Int	SIDA
Dushanbe	25-Jun	46-44-190	27-Aug	15.72	Int	SIDA

Dushanbe	25-Jun	04-46-121	26-Jul	15.23	Int	SIDA
Dushanbe	25-Jun	22-25-145	26-Jul	19.93	Int	SIDA
Dushanbe	25-Jun	44-05-198	27-Aug	13.90	Int	SIDA
Khorog	6-Jul	24-56-124	11-Jul	17.27	Int	Savob
Khujand	19-May	44-06-186	17-Jun	16.23	Int	B. Gafurov
Khujand	19-May	01-55-114	20-May	33.80	Int	Chkalovsk
Khujand	19-May	37-38-165	17-Jun	10.02	Int	B. Gafurov
Khujand	19-May	53-48-197	22-Jun	28.15	Int	Khujand
Khujand	20-May	27-45-140	24-May	16.55	Int	Khujand
Khujand	20-May	59-34-107	24-May	19.58	Int	Khujand
Khujand	20-May	32-27-154	24-May	22.28	Int	Khujand
Khujand	20-May	59-11-112	24-May	14.00	Int	Khujand
Khujand	20-May	20-55-152	25-May	17.48	Int	Khujand
Khujand	20-May	47-57-187	17-Jun	16.87	Int	Khujand
Khujand	20-May	06-13-158	17-Jun	16.53	Int	Khujand
Khujand	20-May	25-24-133	25-May	15.53	Int	Khujand
Khujand	20-May	43-32-174	17-Jun	12.58	Int	Khujand
Khujand	21-May	59-30-116	11-Jul	9.30	Int	Khujand
Khujand	21-May	07-54-177	11-Jul	19.22	Int	Khujand
Khujand	21-May	37-03-117	31-May	49.95	Int	Rangikamon
Khujand	22-May	23-14-161	17-Jun	8.58	Int	Chkalovsk
Khujand	22-May	33-29-124	28-May	8.57	Int	Chkalovsk
Khujand	22-May	00-21-188	17-Jun	5.67	Int	Chkalovsk
Khujand	22-May	06-29-150	30-May	12.42	Int	Chkalovsk
Khujand	22-May	13-53-143	17-Jun	11.53	Int	Chkalovsk
Khujand	22-May	13-53-143	22-Jun	11.53	Int	Chkalovsk
Khujand	22-May	52-51-150	17-Jun	16.67	Int	Chkalovsk
Khujand	22-May	45-50-104	30-May	26.30	Int	B. Gafurov
Khujand	22-May	19-35-109	30-May	13.48	Int	Chkalovsk
Khujand	22-May	06-29-150	30-May	12.42	Int	B. Gafurov
Khujand	22-May	44-19-108	17-Jun	15.25	Int	B. Gafurov
Khujand	22-May	33-29-124	28-May	8.57	Int	B. Gafurov
Khujand	22-May	09-35-194	25-May	12.97	Int	Chkalovsk
Khujand	3-Nov	54-15-181	4-Dec	50.25	Int	Nazira
Average Focus Group		48.51				
Average Interview						
	Bokhtar	17.69	Dushanbe	25.05		
	Khujand	17.74				

Doc #	Project Title	Year	Lead	Document(s)	Source
1	Конф. Общесвенные услуги для детей с особенности в псих. Развития	2002	Operational	Participant list	OSI Tajikistan
2	Annual Report	2002	OSI Tajikistan	Annual Report	OSI Tajikistan
3	Проект Спасение детей	2002	Душанбинская территориально первичная организация общества слепых	Заявка и отчет	OSI Tajikistan
4	16 дней против насилия	2003	Начоти Кудакон	Proposal & Report	OSI Tajikistan
5	Малий грант для работы с ПМПК	2003	ОО Здоровье	Proposal & Report	OSI Tajikistan
6	Annual Report	2004	OSI Tajikistan	Annual Report	OSI Tajikistan
7	Гранты для развития женских кризисных центров	2004	Начоти Кудакон	Proposal & Report	OSI Tajikistan
8	Семейный консультативно образовательный центр для родителей с особыми детьми	2004	ОО Здоровье	Proposal & Report	OSI Tajikistan
9	Annual Report	2005	OSI Tajikistan	Annual Report	OSI Tajikistan
10	4я модельная площадка для стран ЦА: комлексная модель ценрта социализации людей с отклонениями в умственном развитии	2005	Начоти Кудакон	Participant list	OSI Tajikistan
11	Annual Report	2006	OSI Tajikistan	Annual Report	OSI Tajikistan
12	Гранты для развития женских кризисных центров	2006	Начоти Кудакон	Proposal & Report	OSI Tajikistan
13	Annual Report	2007	OSI Tajikistan	Annual Report	OSI Tajikistan
14	Кампания на день защиты детей	2007	ОО АРДОВ г. Душанбе	Proposal & Report	OSI Tajikistan

15	Annual Report	2008	OSI Tajikistan	Annual Report	OSI Tajikistan
16	Вместе на жизнь	2008	Комитет родителей и воспитателей спец. Детского сада #151	Proposal & Report	OSI Tajikistan
17	Первые шаги в школу	2008	ОО АРДОВ г. Душанбе	Proposal & Report	OSI Tajikistan
18	Dushanbe: Disabled Children's Advocacy Network, Tajikistan	2009	Education Support Program	Proposal & Report	Open Society Foundations
19	Annual Report	2009	OSI Tajikistan	Annual Report	OSI Tajikistan
20	Пить к новой жизни	2009	Иниц. Группа родителей ДОВ г. Исфара	Proposal & Report	OSI Tajikistan
21	Создание ассоциации родителей ДОВ в г. Худжанде	2009	Иниц. Группа родителей ДОВ г. Худжанда	Proposal & Report	OSI Tajikistan
22	Проект "Менторинг и Мониторинг проектов по обеспечению доступа к качественному образованию детей со спец. Нуждами	2009	ОО АРДОВ г. Душанбе	Proposal & Report	OSI Tajikistan
23	Партнерский проект с Международной Волонтерской Организацией	2009	ОО АРДОВ г. Душанбе	Proposal & Report	OSI Tajikistan
24	Инклюзивное образование на дошкольном уровене для детей с особенностями психического развития	2009	ОО Здоровье	Proposal & Report	OSI Tajikistan
25	Создание ассоциации родителей ДОВ в Бохтарском регионе	2009	ОО Фуруги маърифат	Proposal & Report	OSI Tajikistan
26	Создание ассоциации родителей ДОВ в г. Хороге	2009	ОО Хохарон	Proposal & Report	OSI Tajikistan
27	APDC's Overall Report and Recommendations (J. Baker)	2010	Education Support Program	Consultant Report	Open Society Foundations
28	Dushanbe: Parent Empowerment Program, Tajikistan	2010	Education Support Program	Proposal & Report	Open Society Foundations

29	Annual Report	2010	OSI Tajikistan	Annual Report	OSI Tajikistan
30	Конкурс проектов на поддержку Ассоциаций и иниц. Групп родителей ДОВ	2010	АРДОВ г. Хорог	Proposal & Report	OSI Tajikistan
31	Конкурс проектов на поддержку Ассоциаций и иниц. Групп родителей ДОВ	2010	Иниц. Группа родителей детей с аутизмом г. Душанбе	Proposal & Report	OSI Tajikistan
32	Конкурс проектов на поддержку Ассоциаций и иниц. Групп родителей ДОВ	2010	Иниц. Группа родителей ДОВ "Нури офтоб" Гиссарский район	Proposal & Report	OSI Tajikistan
33	Конкурс проектов на поддержку Ассоциаций и иниц. Групп родителей ДОВ	2010	Иниц. Группа родителей ДОВ, Хатлонская обл. Вахшский район	Proposal & Report	OSI Tajikistan
34	Конкурс проектов на поддержку Ассоциаций и иниц. Групп родителей ДОВ	2010	Маркази дастгирии Чамоати Галаба, нохияи Фархор	Proposal & Report	OSI Tajikistan
35	Конкурс проектов на поддержку Ассоциаций и иниц. Групп родителей ДОВ	2010	Начоти Кудакон	Proposal & Report	OSI Tajikistan
36	Поддержка ОО "Спешал Олимпикс Таджикистана" на проведение соревнований по легкой атлетике для ДОВ	2010	ОО "Спешал Олимпикс Таджикистана"	Proposal & Report	OSI Tajikistan
37	Конкурс проектов на поддержку Ассоциаций и иниц. Групп родителей ДОВ	2010	ОО Комитет родителй ДОВ г. Исфара	Proposal & Report	OSI Tajikistan
38	Проект по вопросам раннего скрининга	2010	ОО Маркази Нур	Proposal & Report	OSI Tajikistan
39	Конкурс проектов на поддержку Ассоциаций и иниц. Групп родителей ДОВ	2010	ОО Родителеи детей с проблемами в развитии г. Худжанд	Proposal & Report	OSI Tajikistan
40	Trip Report (Kate Lapham - November)	2011	Education Support Program	Internal document	Open Society Foundations
41	American Bar Association Training for Parent Associations	2011	Education Support Program	Proposal & Report	Open Society Foundations
42	Annual Report	2011	OSI Tajikistan	Annual Report	OSI Tajikistan

43	Содействие в интеграции ДОВ в общество	2011	АРДОВ "Савоб" Шугнанский пайон	Proposal & Report	OSI Tajikistan
44	Образование для всех	2011	АРДОВ Бохтарского района	Proposal & Report	OSI Tajikistan
45	Школа для всех	2011	Комитет родителей и воспитателей спец. Детского сада #151	Proposal & Report	OSI Tajikistan
46	Улудшение доступа родителей ДОВ к базовым услугам	2011	Начоти Кудакон	Proposal & Report	OSI Tajikistan
47	Протяни руку первым	2011	ОО «ИРОДА»	Proposal & Report	OSI Tajikistan
48	Report	2011	ОО АРДОВ г. Бохтар	Proposal & Report	OSI Tajikistan
49	Старший брат и старшая сестра	2011	ОО Комитет родителй ДОВ г. Исфара	Proposal & Report	OSI Tajikistan
50	Проект по вопросам раннего скрининга	2011	ОО Маркази Нур	Proposal & Report	OSI Tajikistan
51	Раннее выявление и ранная помощь детям с отставанием в развитии и семьям	2011	ОО Рангикамон	Proposal & Report	OSI Tajikistan
52	Объедининие в пользу развития родителей ДОВ	2011	ОО Родителеи детей с проблемами в развитии г. Худжанд	Proposal & Report	OSI Tajikistan
53	Раннее детское вмешательство и инклюзивное образование	2011	ОО родителей «Дунеи кудакон»	Report	OSI Tajikistan
54	Report on training for the network of Parent Associations in Tajikistan (J. Baker)	2012	Education Support Program	Consultant Report	Open Society Foundations
55	Central Asia Autism Network Report (J. Baker)	2012	Education Support Program	Consultant Report	Open Society Foundations
56	Trip Report (Kate Lapham - January)	2012	Education Support Program	Internal document	Open Society Foundations

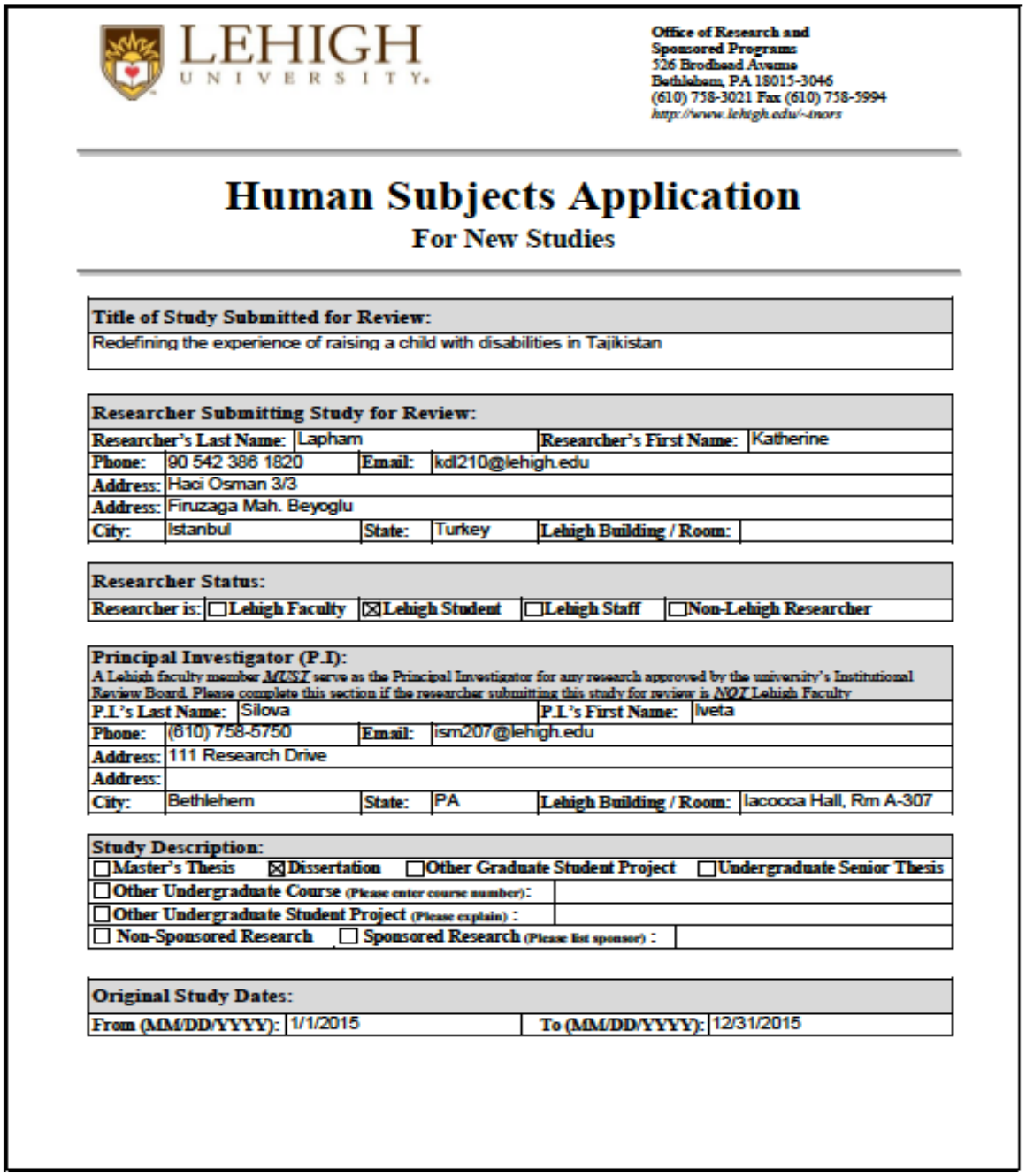
57	Dushanbe: Promote Inclusive Education in Russia and Tajikistan	2012	Education Support Program	Proposal & Report	Open Society Foundations
58	Dushanbe: Annual APDC Meeting	2012	Education Support Program	Proposal & Report	Open Society Foundations
59	Dushanbe: Rehabilitation Center for Children with Disabilities, Dushanbe	2012	Education Support Program	Proposal & Report	Open Society Foundations
60	Community Mapping and Statistical Research Project, 2010-11 (Molnar & Hakimzoda)	2012	ОО АРДОВ г. Душанбе	Research Report	Open Society Foundations
61	Annual Report	2012	OSI Tajikistan	Annual Report	OSI Tajikistan
62	Школа для всех	2012	Комитет родителей и воспитателей спец. Детского сада #151	Proposal	OSI Tajikistan
63	Повышение активности участия родителей ДОВ в процессе вовлечения	2012	Начоти Кудакон	Proposal & Report	OSI Tajikistan
64	Создание Службы ранней помощи в Исфаринском районе	2012	Общественная Организация «Рангинкамон»	Proposal	OSI Tajikistan
65	Партнерство на пути к инклюзии	2012	ОО «ИРОДА»	Proposal & Report	OSI Tajikistan
66	Подготовка детей с особыми нуждами к школе	2012	ОО Комитет родителей и учителей спец. Школы детей с нарушением слуха #8	Proposal & Report	OSI Tajikistan
67	Организация служб по оказанию ранней помощи детям с особенностями психофизического развития и их родителям по ГБАО	2012	ОО Маркази Нур	Proposal & Report	OSI Tajikistan
68	Раннее выявление и ранняя реабилитация детей, имеющих психические и физические остсавания в развитии	2012	ОО Рангикамон	Proposal & Report	OSI Tajikistan

69	Жить вместе, учиться и радоваться вместе	2012	ОО Родители ДОВ "Савоб"	Proposal & Report	OSI Tajikistan
70	Trip Report (Kate Lapham - November)	2013	Education Support Program	Internal document	Open Society Foundations
71	Trip Report (Lapham - April)	2013	Education Support Program	Internal document	Open Society Foundations
72	Associations Survey Overview (Lapham)	2013	Education Support Program	Internal document	Open Society Foundations
73	Annual Report	2013	OSI Tajikistan	Annual Report	OSI Tajikistan
74	Продвижение прав и интересов детей с особыми потребностями и ОВ в Таджикистане	2013	Нац. Коалиция ОО АРДОВ	Proposal & Report	OSI Tajikistan
75	General Support	2013	ОО «ИРОДА»	Proposal & Report	OSI Tajikistan
76	Развитие ресурсной платформы по внедрению современных подходов к обучению детей и подростков с нарушениями аутуистического спектра и инклюзии	2013	ОО «ИРОДА»	Proposal & Report	OSI Tajikistan
77	Инклюзивное образование для детей с нарушениями психического здоровья	2013	ОО Здоровье	Proposal & Report	OSI Tajikistan
78	Организация служб по оказанию ранней помощи детям с особенностями психофизического развития и их родителям по ГБАО	2013	ОО Маркази Нур	Proposal & Report	OSI Tajikistan
79	Вместе мы сможем	2013	ОО Рушди инклюзия	Proposal & Report	OSI Tajikistan
80	IRODA: Strengthening Early Childhood Services in Tajikistan: Effective Partnerships Towards Inclusion	2014	Early Childhood Program	Proposal & Report	Open Society Foundations
81	Trip Report (Olena Sydorenko)	2014	Education Support Program	Internal document	Open Society Foundations

82	Trip Report (Early Childhood Program - March)	2014	Education Support Program	Internal document	Open Society Foundations
83	Coalition Meeting Report	2014	Education Support Program	Internal document	Open Society Foundations
84	Funding Table for APDC's 2010-13	2014	Education Support Program	Internal document	Open Society Foundations
85	Khujand: Coalition of parent organizations: Promoting inclusion of children with disabilities in Tajikistan	2014	Education Support Program	Proposal & Report	Open Society Foundations
86	Организация служб по оказанию ранней помощи детям с особенностями психофизического развития и их родителям по ГБАО	2014	ОО «Маркази Нур»	Report	OSI Tajikistan
87	Annual Report	2014	OSI Tajikistan	Annual Report	OSI Tajikistan
88	General Support	2014	ОО «ИРОДА»	Proposal & Report	OSI Tajikistan
89	Эффективное партнерство на пути к инклюзии	2014	ОО «ИРОДА»	Report	OSI Tajikistan
90	Ранне вмешательство путь к инклюзивному образованию	2014	ОО АРДОВ Хатлонской области	Proposal & Report	OSI Tajikistan
91	Учимся вместе	2014	ОО АРДОВ Хатлонской области	Proposal & Report	OSI Tajikistan
92	Ранне вмешательство путь к инклюзивному образованию	2014	ОО АРДОВ Хатлонской области	Report	OSI Tajikistan
93	Ранне вмешательство путь к инклюзивному образованию	2014	Раннее вмешательство путь к инклюзивному образованию	Report	OSI Tajikistan
94	Развитие устойчивого партнерства на пути к инклюзии	2014	Родительская организация ДОВ «Савоб»	Report	OSI Tajikistan

95	Trip Report (Kate Lapham - November)	2015	Education Support Program	Internal document	Open Society Foundations
96	Khujand: Coalition of parent organizations: Promoting inclusion of children with disabilities in Tajikistan/2015	2015	Education Support Program	Proposal & Report	Open Society Foundations
97	Interim Report to Caritas	2015	NGO "Rangikamon"	Report	OSI Tajikistan
98	General Support	2015	ОО «ИРОДА»	Proposal & Report	OSI Tajikistan
99	Khorog: Coalition of parent organizations: Promoting inclusion of children with disabilities in Tajikistan/2016	2016	Education Support Program	Proposal & Report	Open Society Foundations

Appendix 5: Application to Institutional Review Board for Research with Human Subjects



LEHIGH UNIVERSITY

Office of Research and Sponsored Programs
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Bethlehem, PA 18015-3046
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http://www.lehigh.edu/~inors

Human Subjects Application

For New Studies

Title of Study Submitted for Review:
Redefining the experience of raising a child with disabilities in Tajikistan

Researcher Submitting Study for Review:					
Researcher's Last Name:	Lapham			Researcher's First Name:	Katherine
Phone:	90 542 386 1820	Email:	kdl210@lehigh.edu		
Address:	Haci Osman 3/3				
Address:	Firuzaga Mah. Beyoglu				
City:	Istanbul	State:	Turkey	Lehigh Building / Room:	

Researcher Status:				
Researcher is:	☐ Lehigh Faculty	☒ Lehigh Student	☐ Lehigh Staff	☐ Non-Lehigh Researcher

Principal Investigator (P.I.): A Lehigh faculty member *MUST* serve as the Principal Investigator for any research approved by the university's Institutional Review Board. Please complete this section if the researcher submitting this study for review is *NOT* Lehigh Faculty					
P.I.'s Last Name:	Silova			P.I.'s First Name:	Iveta
Phone:	(610) 758-5750	Email:	ism207@lehigh.edu		
Address:	111 Research Drive				
Address:					
City:	Bethlehem	State:	PA	Lehigh Building / Room:	Iacocca Hall, Rm A-307

Study Description:			
☐ Master's Thesis	☒ Dissertation	☐ Other Graduate Student Project	☐ Undergraduate Senior Thesis
☐ Other Undergraduate Course (Please enter course number):			
☐ Other Undergraduate Student Project (Please explain) :			
☐ Non-Sponsored Research	☐ Sponsored Research (Please list sponsor) :		

Original Study Dates:			
From (MM/DD/YYYY):	1/1/2015	To (MM/DD/YYYY):	12/31/2015

Type of Review:
Using the following criteria and examples as a guide, select the type of review you feel is appropriate for your study. For more information on the types of review conducted by the IRB please see the Lehigh University Human Subjects Policy (available at www.lehigh.edu/~inors/HSPolicy.doc.).

☐ **Exempt Review**

Proposals are exempt from more detailed review if the research described poses minimal risks to subjects and proper procedures are used to implement ethical principles for the protection of human subjects. The chair of the IRB determines whether a research project will classified as "Exempt.". As necessary, the chair will consult with other IRB members when making this decision. The following types of research may fall into the exempt category:

- Anonymous survey / interview procedures or observation (without intervention) of public behavior
- Survey / interviews in which the participant can be linked and information obtained is innocuous
- Study of existing data or pathological specimens if information is recorded anonymously. Disclosure of this information would NOT reasonably place the participant at risk of criminal or civil liability or damaging to the participants' financial standing, employability or reputation.
- Review Status Definitions

☒ **Expedited Review**

The expedited review category is used for certain types of research involving no more than minimal risk and minor changes to research previously approved by the full committee, during the period for which approval has been authorized. Proposals are reviewed by three members of the University's IRB. Agreement of all reviewers is needed for approval. Reviewers may refer the proposal to the full committee. The following types of research may fall into the expedited review category:

- Surveys which can be linked to participant and may request "sensitive" information
- Blood draws
- Non-stressful research on individuals or group behavior
- Study of existing data or pathological specimens if information recorded can be linked to participant
- Recording of data using non-invasive procedures

☐ **Full Committee Review**

Any research not covered under the exempt or expedited review categories is referred to the IRB for full committee review. The principal investigator may be invited to attend the review. The committee will either: (i) approve the research; (ii) approve the research pending modifications that must be verified by committee members; or (iii) not approve the research. The committee will notify the principal investigator in writing about the committee's decision. The following types of research may fall into the expedited review category:

- Surveys Invasive medical treatments
- Physical or Psychological risk
- Special Populations (minors, pregnant women, prisoners, incompetent persons)

Additional Items Required for IRB Review:

☒ Informed Consent or request for waiver of Informed Consent	☒ Instruments (Surveys, tests, ect)
☒ Full Proposal (Dissertation, Sponsor Application, ect)	
☒ Certification of completion of online tutorial (http://phrp.nihtraining.com/users/login.php)	
☐ Letter of Approval (For research conducted in K-12 schools)	

Subject Characteristics:

Sex: ☐ **Male** ☐ **Female** ☒ **Both** **Number of Subjects:** 190

Age Range (in years) **From:** 18 **To:** 80

Subjects may include: ☐ **Minors** ☐ **Pregnant Women** ☐ **Incompetent to Consent** ☐ **Prisoners**

Subjects' general state of health: mentally and physically capable

Please provide the following information for the review of your new study:

1. **Summarize the purpose of the proposed research, making clear the research question(s) and hypothesis(es). Avoid the use of technical terms or discipline specific language. Your explanation must be concise and clear to those unfamiliar with your field. Please describe all study procedures and limit your summary to one page.**

This dissertation explores the relationship between empowerment and social capital formation among mothers of children with disabilities in Tajikistan as a result of their participation in parent associations. Mothers of children with disabilities in Tajikistan face extreme social stigma because of traditional beliefs that their child's disability is a reflection of their own sinful behavior. This results in a wide variety of overt discrimination for both mother and child. This can include institutionalization of children from birth, withholding medical care at birth or in early childhood, purposefully mislabeling a disability as "birth trauma" in hopes of protecting the mother, and hiding children with disabilities at home. For the mother, consequences can include limited marriage prospects for her other children, divorce, significantly reduced social status, and outright abuse within her marriage family or her birth family if she is forced to return to them following a divorce. The Soviet legacy of defectology reinforces this marginalization by framing disability as a defect within the child that requires correction through specialized services and segregated schooling in order for later participation or inclusion in broader society. Furthermore, formal public provision of specialized services in Tajikistan has largely disintegrated in the economic deprivation following the disintegration of the Soviet Union and the chaos of the civil war.

Within this context civil society organizations concerned with women's health and international organizations, including the Open Society Foundations, have sought to provide support for mothers of children with disabilities. In hopes of helping them through post-partum depression and the psychological pain of isolation, they have supported group therapy and self-help groups. One of these support groups, incubated in the NGO Zdorovye and with support from the Open Society Foundations, formed an association of parents of children with disabilities in Dushanbe in 2007. The original goal of the association was to continue to support parents psychologically but also to provide services, like physical or occupational therapy, for children. It has also enabled parents to learn as much as possible about their children's disability, collecting or pooling resources to purchase equipment, and developing community-based service delivery.

When little is available publicly and services are created from scratch, there is significant space for innovation, which can be a great advantage. However, this also requires a great deal of motivation, self-confidence, and assertiveness from the initial group of participants to develop these models and continued outreach to the community to ensure their sustainability. Furthermore, as the parent association in Dushanbe has expanded to support initiative groups or find like-minded partner associations in other regions, an infant advocacy coalition has developed that networks parents of children with disabilities from Penjikent on the border with Uzbekistan to Murgab at the edge of the Pamirs. Together at the national level and individually within their own communities, they advocate for access to education, healthcare, and social benefits as well as working to create a more positive view of disability among the general public.

In the face of such huge barriers that include social stigma, discrimination within their own families, poverty, and lack of services, how have these women become empowered advocates for themselves and their children? This research will develop three cases studies of parent groups in different parts of Tajikistan (Dushanbe, Khujand, Bokhtar) and with varying profiles (autism, general disability) in addressing the research question. Building on the broad and multi-disciplinary literature on empowerment and social capital formation, this dissertation explores the relationship between empowerment and social capital that grows from crisis or need to gaining knowledge through support from others. The objective is examine whether and how such partnerships, in turn, lead to increased confidence among women and a desire to work together in support of others, while nurturing a growing feeling of self-worth and self-efficacy.

This research has the potential to make a significant contribution to several bodies of literature. Although there is an existing literature on social capital formation among parents of children with disabilities, most studies focus on North America or Western Europe. Tajikistan is a severely under-researched geography, but even in the broader context of developing world similar studies are rare. In addition, this research brings together literature in fields that include community psychology, social work, political science and

development studies, and sociology to develop a cross-disciplinary model of empowerment. Finally, this dissertation also has the potential to contribute to research on civil society development and participation by focusing on the phenomenological relationship between social capital formation and empowerment through participation in formal (registered NGOs) and informal associations.

The proposed cases will be developed using qualitative research methods, including interviews and focus groups with key informants, observations of activities within the parent groups, and analysis of documents produced by the groups. These cases will apply the model of interaction between social capital and empowerment with a particular practical focus on access to education. Although all public services are important, education is most likely to be available in every community through local schools. It is also likely to be one of the more difficult for children with disabilities to access because of the Soviet legacy of education segregated by disability type. In Tajikistan, the special education system is not readily accessible because there are few schools in operation. Yet in local schools, teachers have little or no training in inclusive education and do not feel prepared to include children with disabilities in their classrooms. This point of interaction between parent and teacher, family and school is a critical test of the parent association's ability not only to advocate for access but to develop the relationships and provide the support to make access meaningful and sustainable.

This research seeks to determine whether and how the associations have empowered parents as well as their strength as organizations capable of surviving, and more importantly, determining their mission independently.

1. Under what circumstances do mothers of children with disabilities in Tajikistan build social capital when they participate in groups with other parents?
   a. What combinations of bonding and bridging social capital are produced?
   b. How do these connections evolve over time in the different settings of the three cases?
   c. Do mothers of children with disabilities report that these experiences are empowering in terms of increased knowledge, increased confidence and community action?
   d. Does the profile of the mothers change from founding to later members?
2. What types of initiatives, particularly in education, are emerging from the parent groups in the three cases?
   a. When and how did they emerge? To what extent are they attributed to social capital built within the group?
   b. How do other members of the community perceive these initiatives?
3. What are the implications of these experiences of community action for individuals and communities?

Tentative timeline

This research project includes a review of relevant academic literature and background information in the summer and autumn of 2014. Approval for work with human subjects will be sought from Lehigh University's Institutional Review Board (IRB) in the first quarter of 2015. Field research is dependent on a sabbatical from the Open Society Foundations and is planned for 10 weeks in the spring of 2015 in Tajikistan. Analysis of the field research and writing up of findings and conclusions in planned for the summer and early autumn of 2015. If research progresses along this timeline, revision and defense of the resulting dissertation should be possible by the beginning of 2016.

2. **Describe the research design. Specify how the data will be used to answer the proposed research question(s). Provide the name of each of the measures that will be used (attach a copy of each), provide information on the reliability and validity of each measure (references or results from prior use of the measure). State the details of the statistical or qualitative analysis that will be used to analyze these data.**

This study will use qualitative research methods to develop multiple (3) case studies of parents participating in different types of associations in different regions of Tajikistan. I will use one-to-one, very loosely structured interviews with mothers who have made efforts within each of these cases to find each other and to advocate for their children. The primary areas of interest to be explored through the interview protocols include the motivation for parents to come together in mutual support groups, parents' experience of advocating for their children within their families and communities, and perceived changes in relationships, self-view and world-view research participants associate with participation in such groups. Since this dissertation is proposed for a degree in Comparative and International Education, I will be especially interested in parents' decisions to support inclusive education for their children and others in the community. This will provide them with the maximum possible privacy to tell their stories, which may be emotional. I will also use their responses as a guide for further questions and the timing of the

interview so that we can build trust for the discussion of difficult topics. For the same reason, I will also allow time for more than one session with each of these mothers, as additional questions may arise through ongoing field research.

In order to develop a rigorous approach to my research questions, I have sought the models and instruments that other researchers have used to answer similar types of questions with populations as comparable as possible. In order to gather information about social capital among the mothers within each of the three cases, I will use a modified framework of questions originally used by Bates and Davis (2004, p. 196) to define parameters of social capital in rural communities in the United Kingdom. These questions are contextualized to Tajikistan using the research of Collette Harris on gender roles and family structure. Please see the attached research instruments in Annex 1 of the full proposal for more information.

3. **If subjects are either (A) children, (B) mentally incompetent, or (C) legally restricted (i.e., institutionalized), please explain necessity for using this particular group. [Studies using these populations always involve some risk, Question #11 must be answered]**

N/A

4. **How will the subjects be sampled, recruited or otherwise enlisted as subjects in this study? If subjects are recruited from a school, an institution (group home, church, adult day care, etc.), a university, or a similar situation where you are collecting data within the confines of the group/institution, documentation must be provided confirming that permission has been obtained from the school administration, a person with authority within the group/institution (professor of a class from another institution that is being recruited), or the director of the program (group home, adult day care, etc.).**

Subjects will be recruited through correspondence with the three organizations participating in the case studies. All subjects will be either leaders of the consitutent associations or active parents / volunteers / staff of the associations. Interviews and focus groups will be arranged by telephone and email prior to travel to Tajikistan.

5. **Describe the manner in which informed consent will be obtained for each appropriate category.**

Adult Subjects:
Includes persons 18 years of age and over. Subject consent required.

I will obtain consent from all interviewees via email or in writing prior to beginning any interviews using the attached form to ensure that all participants are fully informed of their rights and have the opportunity to express any concerns about confidentiality or other ethical implications of the information they provide in support of this research.

Institutionalized Subjects: Subject consent form and consent of appropriate, responsible institutional staff person required.

N/A

Parents/Guardians consent for Child Subjects (Includes all persons under 18):
Written permission is required of both parents or the child's guardian for each child under the age of 18 who will be the subject of research. The permission of one parent is sufficient if: (a) the other parent is not reasonably available or is incompetent; or (b) only one parent has legal responsibility for the care and custody of the child; or (c) the research is such that it either does not involve more than minimal risk to the child or involves more than minimal risk but also presents the prospect of direct benefit to that child. Please provide a justification if you will only be asking for the signature of one parent. Note: Protocols for research being conducted in elementary, middle or high schools must be accompanied by a letter of approval from the principal or superintendent of the school.

N/A

6. If subjects are 14-17, will their written assent be obtained?

☐ Yes ☐ No ☒ No subjects between the ages of 14 and 17 will be recruited.

For more information, please see requirements regarding assent under "Children as Subjects in Research" in the Lehigh University Human Subjects Policy (www.lehigh.edu/~inors/HSPolicy.doc.).

If no, why not? If yes, how?

7. If subjects are 14 and younger, will you obtain their assent?

☐ Yes ☐ No ☒ No subjects age 14 and younger will be recruited.

If no, why not? If yes, how?

8. What precautions will be taken to insure the privacy and confidentiality or anonymity of the subjects? (Please include the reporting of data).

All names of the participants would be coded, such as parent #1, NGO leader #2, etc. In the resulting dissertation, each interview subject will have a pseudonym for both herself and her village to ensure that confidentiality is maintained throughout the study.

9. What specific procedures will be taken to safeguard the data in your possession?

The data obtained in the course of the research, would be in electronic form in computers protected by a username and a password.

10. Are audio or visual images of the subjects going to be recorded?

☒ Yes ☐ No

If yes, the following questions should be addressed:

a. What type of recordings will be made (audio or visual)?

I will use audio recordings of interviews and focus groups to develop transcripts during the process of data analysis. These will be kept in encrypted form on a computer or external hard-drive that is password protected. Relevant documents or artefacts will be copied or photographed. The resulting images will be stored in a similarly secure manner.

b. How will the recordings be utilized in your study or analysis?

Recordings would be utilized mainly for maximizing the interaction time between the interviewer and interviewee, the focus- group participants and the moderator.

c. What specific procedures will be taken to protect the recordings?

The recordings will be kept in a computer protected by a username and password. They will be deleted after the completion of the research.

d. Do you envision any other uses for the recordings, such as illustrations in publications or as a training tool?

N/A

e. Will the recordings eventually be destroyed? When? How?

They will permanently erased from the computer and recording devise after completing the research.

11. Since there are always some risks in any study, even if minimal, describe in detail the possible physical, psychological, social, legal, economic or other risks to the subjects, either immediate or long range. Estimate the seriousness and extent of the risks.

The risks to subjects in this research are minimal. There is a social risk associated with openly claiming a child with disabilities in Tajikistan. The participants in this study will have already taken this risk by joining the associations in the first place; however, the research team will take care to use pseudonyms and location rather than more overtly identifying factors for any qualitative data reported. There is also a physical risk associated with travel in Tajikistan's mountainous areas, which is why the researcher will visit each association or make arrangments to conduct interviews by telephone rather than gathering all subjects in a central location.

12. Describe the procedures that will be used to reduce the risk. How effective do you feel they will be?

I will follow the ethics of data collection and evaluation under the supervision of Dr. Silova. We will also minimize travel for research subjects and insure that identifying data does not appear in the final research report for dissemination to protect research subjects from any social repercussions.

13. Assess the benefits of this research to:

The Subjects

This research will help the NGO leaders participating to strengthen their organizations' capacity to provide services and advocate for the rights of children with disabilities by supplying them with information and recommendations about their management and governance. Furthermore, the research will allow the Open Society Foundations and other donors to better target support to these and similar organizations in Tajikistan.

Society at Large

Society at large will benefit through the promulgation of more positive attitudes toward people with disabilities in their communities and greater understanding of the challenges faced by parents of children with disabilities. It is possible that this research will inform further action to suggest changes to policies and social service provision that will benefit communities beyond people with disabilities.

Do you feel that the benefits significantly outweigh the risks involved?

☒ **Yes** ☐ **No**

Please Explain

The risks are relavitively minimum and the evaluation will provide useful insight into locally developed models of service provision for children with disabilities.

Required Signature Listing:

☒ **Researcher**

Any Researcher submitting a study to the Lehigh Institutional Review Board must

electronically sign the IRBNet package.
☒ **Principal Investigator** **For Student or non-Lehigh Researchers, a Lehigh faculty member must serve as the Principal Investigator for the study and electronically sign the IRBNet package. By electronically signing they certify the following: I am the Principal Investigator for this study; I have examined the procedures involved in this study, and I take overall responsibility for the conduct of this research.**
☐ **Department / Center Approval (if required)**

Appendix 6: Informed Consent Letter

CONSENT FORM

Redefining the experience of raising a child with disabilities in Tajikistan

You are invited to be in a research study of the work of the Coalition of Associations of Parents of Children with Disabilities. You were selected as a possible participant because you are either a member, donor, or partner of one of these associations. We ask that you read this form and ask any questions you may have before agreeing to be in the study. **This study is being conducted by:** Katherine Lapham, PhD candidate in the College of Education, under the direction of Dr. Iveta Silova, College of Education, Lehigh University.

Purpose of the study

The purpose of this study is: To study the ways that parents of children with disabilities build social capital through participation in associations and advocacy coalitions in Tajikistan.

Procedures

If you agree to be in this study, we would ask you to do the following things:

Participate in this interview [or focus group] to share information about the experience of raising a child with disabilities in Tajikistan as well as the nature of your participation in groups or associations formed by parents of children with disabilities.

Risks and Benefits of being in the study

Possible risks: There is minimal risk to you resulting from participation in this study. If there is the possibility that your employer will object to your sharing information with me, then you should check with your immediate supervisor before participating.

The benefits to participation are: *There are no personal benefits to your participation the study; however, you may contribute to improved education for children with disabilities and to the improved functioning of the Coalition and its constituent associations. You will also make a positive contribution to support for children with disabilities and education grant programs in Tajikistan.*

Compensation: You will not receive any payment for participating in this study.

Confidentiality

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a subject. Research records will be stored securely and only researchers will have access to the records. Audio recordings of interviews and focus groups will be used only by the researcher to check her notes. They will be destroyed at the conclusion of the study and will never be released to any third parties or used for any other purpose.

Voluntary Nature of the Study

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the Lehigh University. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions

The researcher conducting this study is: Katherine Lapham. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact her at kdl210@lehigh.edu. You may also contact my advisor, Iveta Silova at ism207@lehigh.edu.

Questions or Concerns: If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact Susan E. Disidore at (610)758-3020 (email: sus5@lehigh.edu) or Troy Boni at (610)758-2985 (email: tdb308@lehigh.edu) of Lehigh University's Office of Research and Sponsored Programs. All reports or correspondence will be kept confidential. ***You will be given a copy of this information to keep for your records.***

Statement of Consent

I have read the above information. I have had the opportunity to ask questions and have my questions answered. I consent to participate in the study.

Signature:	_____	Date	_____
Signature of Parent/Guardian:	_____	Date	_____
Signature of Investigator:	_____	Date	_____

Appendix 7: Research Instruments

Research Instrument 1: Interview with mothers

Profile building questions

1. Demographic information: How old are you? Where did you study? Where did you grow up? When did you get married? What language do you speak at home? How many children do you have and when were they born?
2. Place in the family: Who lives in your household? Who is the head of your family? Who makes decisions that affect you? Describe your father. Describe your husband.
3. Connections in the community: How much time do you spend at home? What do you do when you are away from home? Describe the other families in your community (status and financial independence).
4. Reciprocity: have you done or received a favor from someone living nearby? Do local people look after each other? Who would you turn to for advice or to share some good news?
5. Feelings of trust and safety: What do other members of your family tell people about your child with a disability? Do you think that they feel shame? Do they prefer to keep this private?
6. Perceptions of motherhood: What does it mean to be a mother in Tajikistan? What do people expect from you? What do you do when you feel frustrated with your children?

Building knowledge and social capital - empowerment

7. Connections in the community: How do you meet with the other mothers in the group? Does your family know that you come to meetings?
8. Knowledge: What have you learned from participating in the group? What have you researched on your own? How? Have you shared this with others? What things would you still like to learn?
9. Activism: Have you formally complained about a local service? What have you or the group tried to do to improve conditions for children with disabilities in your community?
10. Education and disability: Where does your child go to school? Where do you think that children with disabilities should go to school? Why?
11. Connections in the community: What changes do you see in yourself since having a child with a disability? Describe your relationship to friends and family members (other mothers) whose children do not have a disability.
12. Connections in the community: Are there new mothers joining the group? Can you describe their family situation?

Research Instrument 2: Focus groups with association members (mothers)

1. When did you join the association?
2. What have you learned as a result of membership in this association of parents?
3. What has been the most valuable activity for you?
4. How often do you meet with other parents? What is useful about this?
5. Have you suggested joining the association to other parents or friends?
6. Has your relationship with your child or with other family members changed since you began coming to the association? If so, how?
7. Has your behavior changed since joining the parent association? If so, what do you do differently now?
8. What do you see as the association's largest impact on you? Your child? Society?

Research Instrument 3: Questions for representatives of donors and state agencies

1. Have you heard of the Association of Parents of Disabled Children? If so, in what context?
2. How would you describe their activities?
3. Do you work directly with the APDC coalition or its members? If so, in what context?
4. What are your impressions of the APDC? Do these organizations play a valuable role? What are their most significant impacts?
5. What are your impressions of the evolving social and political context of Tajikistan?

Research Instrument 4: Questionnaire for association directors

1. Accommodation & Equipment

Please rate your:	
Office Space (source, size)	• Strong • Adequate • Weak
Telephone / Internet	• Strong • Adequate • Weak
Computers	• Strong • Adequate • Weak
Equipment	• Strong • Adequate • Weak
Comfort (heat, water, etc.)	• Strong • Adequate • Weak

Location	• Strong • Adequate • Weak
What is your organization's registration status?	

2. Staffing

How many fulltime staff do you have?	
How many part-time staff do you have?	
How many volunteers do you have?	
Who keeps the books?	
What kind of specialists work with your organization?	• therapist • lawyer • teacher • Other _____
Do you have staff with the qualifications you need?	
If no, who / what type of staff member is missing?	
What additional skills would you like your staff to have?	• word processing • spread sheet / budgeting • presentations • specialist knowledge: _____ • research / community mapping • Other _____

3. Governance/Parental Involvement

Do you have a Board?	Yes No
How many people are on the Board?	2 3 4 5 6 7 or more
How often do they meet?	• Once a month • Once in 2-3 months • Once in 4-6 months • Once in 6-12 months
How many members / parents are part of your association?	
How many of them are active?	
What do active members do?	
Do you have Statutes or by-laws (general assembly of members)?	Yes No
How is strategy determined?	
What is the budget for this year?	$
How is the budget determined?	
Where do you raise funds?	• Donors/iNGOs; • government agencies • individuals • selling services • membership dues • Other _____
Who is responsible for fundraising?	

Do you have the minimum funds necessary to ensure the association's stability (keep office, maintain minimum staff and activities)?	

4. Main Activities and Programs

Direct support to children *Circle all that apply*	• School preparation • After-school tutoring • Therapy (occupational / physical) • Counselling • Other _____
Parent support *Circle all that apply*	• Legal / Advocacy • Counselling / Self-help • Information (about child's disability) • Workshops / Training (specify topic) _____ • Other _____
Other programs *Circle all that apply*	• Education (classes or group work with children) • Advocacy / Public information or programs • Campaigns or temporary programs • Other _____
What does your association do best? What is your most essential activity?	
Ideas for the future – what programs or areas of expertise would you like to develop? *Circle all that apply*	• School preparation • After-school tutoring • Therapy (occupational / physical) • Legal / Advocacy • Education (classes or group work with children) • Public information or programs / Campaigns • Counselling / Self-help • Information (about child's disability) • Other _____

5. Participation in the Coalition

How do you understand the structure of the Coalition of Parent Associations?	• Strong • Adequate • Weak
How often do you contact other members?	• Once a week • Once a month • Once every 2-4 months • Once in 6 months • Other _____
Where is the nearest member organization?	• In this town • Less than 10 km away • Less than 30 km away • Less than 50 km away • More than 50 km away
How do you contact other members?	• Telephone • Email • Visits • Formal meetings • Other _____
What do you usually discuss? What are the questions or activities that you have in common?	
Why is it useful to be part of a coalition? What do you get from this?	
What do you contribute to the coalition? Is there something else – a program or area of expertise – that you would like to contribute but have not had the opportunity?	
What are the challenges to the coalition?	
What should the coalition plan to do in the future?	

Research Instrument 5: Questionnaire for mothers

When were you born?		
Where did you grow up?		
Where did you study?		
When did you get married?		
What language do you speak at home?		
How many sons and daughters do you have and when were they born? Boy (19xx) Girl (19xx)	1. 2. 3. 4. 5.	
Which child has a disability? What are his / her challenges?		
Who lives in your household?	Husband Husband's Father Husband's Mother Husband's Siblings Other:	My Children My Father My Mother My Siblings

Who is the head of your family?	
Please describe your father. • When & where was he born? • Where did he study? • What was his profession? • Is he still living? Nearby?	
Please describe your husband. • When & where was he born? • Where did he study? • What is his profession?	

Research Instrument 6: Focus Group – founders and leadership

1. Can you talk a little about the history of the organization?
2. How many parents were there at the time, when you started?
3. How have you found new members / parents? How have they found you?
4. If we return to the beginning – that first activity – how did you find the first 20 families?
5. Why did you decide that you need to support other families? Do you see changes in families after they join the association?
6. Have you cooperated with any government institutions, like schools or polyclinics? If so, what do you get from this?
7. What do they get from this? Why is it interesting for them to work with you?
8. What questions do the clinic directors or school principals ask when you try to establish cooperation?
9. Do you think that others in the community, people without children with disabilities, benefit from your work with government institutions? If so, do they recognize this?
10. When and why did you begin networking with other civil society organizations? Which ones? Are these your partners in the Coalition? In other countries?
11. What are your plans for the future? What do you need for this? What changes?

Appendix 8: Terms of Reference for Research Assistant

Redefining the experience of raising a child with disabilities in Tajikistan

This dissertation explores the relationship between empowerment and social capital formation among mothers of children with disabilities in Tajikistan as a result of their participation in parent associations. Civil society organizations concerned with women's health and international organizations, including the Open Society Foundations, have sought to provide support for mothers of children with disabilities. In hopes of helping them through post-partum depression and the psychological pain of isolation that can come with having a child with a disability, they have supported group therapy and self-help groups. One of these support groups, incubated in the NGO *Zdorovye* and with support from the Open Society Foundations, formed an association of parents of children with disabilities in Dushanbe in 2005. The original goal of the association was to continue to support parents psychologically and also to provide services, like physical or occupational therapy, for children.

In the face of barriers that include social stigma, isolation within their own families, poverty, and lack of services, how have these women become empowered advocates for themselves and their children? This research will develop three cases studies of parent groups in different parts of Tajikistan (Dushanbe, Khujand, Bokhtar) and with varying profiles (autism, Down Syndrome, general disability) in hopes of illuminating this phenomenon. Building on the broad and multi-disciplinary literature on empowerment and social capital formation, this dissertation explores the hypothesis that there is a relationship between empowerment and social capital that grows from crisis or need to gaining knowledge through support from others. This, in turn, leads to increased confidence and a desire to work together in support of others that supports a growing feeling of self-worth and self-efficacy. This continues in an upward spiral building mutually reinforcing individual empowerment and social capital within the group.

The proposed cases will be developed using qualitative research methods, including interviews and focus groups with key informants, observations of activities within the parent groups, and analysis of documents produced by the groups. These cases will apply the model of interaction between social capital and empowerment with a particular practical focus on access to education. Although all public services are important, education is most likely to be available in every community through local schools. It is also likely to be one of the more difficult for children with disabilities to access because of the Soviet legacy of education segregated by disability type.

The primary researcher is seeking a research assistant to support this project. The research assistant will:

- Organize the timetable of interviews and focus groups in agreement with the researcher;
- Provide transcription in Russian (including for interviews and focus groups conducted in Tajik) in MS Word format;
- Translate research instruments into Russian and Tajik, as needed (not more than 10 pages);

- Accompany the researcher to Khujand and Bokhtar;
- Participate in interviews and focus groups as a Tajik – Russian translator when needed;
- Make travel arrangements and provide administrative support as needed.

The table below provides a summary of the expected numbers and locations of interviews and focus groups as well as preliminary dates. At least 10 working days in each research site are expected for the primary researcher. The workload for the research assistant may be slightly less in Dushanbe and Khujand where Russian-language is more widespread.

	Mothers (Interviews)	**NGO Directors (Interviews)**	**Mothers (Focus Groups)**	**Dates**
Case 1: IRODA, Dushanbe	15	1	2 (5-7 participants)	April 25 – July 1
SIDA, Dushanbe	15	1	2 (5-7 participants)	
Case 2: APDC, Khujand	15	1	2 (5-7 participants)	May 2015
Case 3: APDC, Bokhtar	15	1	2 (5-7 participants)	May 2015
Background information (state agencies, donors, iNGOs)	0	0	0	Continuous
Total Events	60	4	8*	

Compensation for this work is based on mutual agreement of $300 / month. The primary researcher will cover round-trip travel expenses one time for each research trip to Bokhtar and Khujand as well as any project related expenses (copying, transportation) in Dushanbe. Upon successful completion of the project, the primary researcher will provide the assistant with a letter of recommendation.

Katherine Lapham, Primary Researcher

Signature: _____ Date: _____

Bibiizzati Amonkulov, Research Assistant

Signature: _____ Date: _____

Appendix 9: Association Directors Survey Summary

1. Accommodation and Equipment

Please rate your:	
Office Space (source, size)	• Strong (7) • Adequate (16) • Weak (5)
Telephone / Internet	• Strong (5) • Adequate (13) • Weak (7)
Computers	• Strong (4) • Adequate (14) • Weak (7)
Equipment	• Strong (4) • Adequate (12) • Weak (9)
Comfort (heat, water, etc.)	• Strong (2) • Adequate (12) • Weak (11)
Location	• Strong (4) • Adequate (16) • Weak (5)
What is your organization's registration status	• National (5) • Local (17) • None (2) • No response (7)

Do you have a license for educational activities?	Yes = 2 No = 24 No response = 5

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2. Staffing

How many staff members do you have?	Average 4.08
How many of them are part-time?	Average 2.64
How many volunteers do you have?	Average 8.24
Who keeps the books?	Director = 3 Accountant = 19 No response = 9
What type of taxes does your organization pay?	Not enough responses to tabulate.
What kind of specialists work in your organization?	• Therapist (4) • Lawyer (3) • Teacher (23) • Other (0)
Do you have staff with the qualifications you need?	Yes = 1 No = 23 No response = 7

If not, who or what type of staff member is missing?	• Speech therapist (10) • Physical therapist (11) • Masseur (1) • Psychologist / therapist (14) • Social worker (6) • Special education teacher (7) • Lawyer (5) • Accountant (0) • Secretary (0) • Tutor / teaching assistant (2)
What additional skills would you like your staff to have?	• Word processing (11) • Spread sheet / budgeting (17) • Presentations (14) • Research / community mapping (16) • Specialist knowledge (9) • Other: proposal writing (5)

3. Governance / Parental Involvement

Do you have a Board?	Yes = 21 No = 4 No response = 6
How many people are on the Board?	2(2) 3(5) 4(5) 5(3) 6(1) 7 or more (5)
How often does your Board meet?	• Once a month (5) • Once every 2-3 months (11) • Once every 4-6 months (15) • Once every 6-12 months (11) • No response (
How many parents are members of your association?	Total: 2,324 Average: 89.4

How do parents learn about your activities or become members of your association?	Word of mouth (9) Referred by PMPC or state agency (8) Media (8) Leaflets (3) Events (12)
How many members are active? What do they do?	Total: 316 Average: 12.2
Do you have a Charter or Statutes?	Yes = 25 No = 1 No response = 5
How is strategy determined? Not enough responses to tabulate.	• Board alone • Board and director • Members • Director alone
What is the budget for this year?	Total: $234,747 Average: $9,781
How is the budget determined?	• Board (0) • Director (1) • Accountant based on existing projects (15) • General Assembly (0) • No response (15)
Where do you raise funds?	• Donors / international organizations (13) • Government agencies (9) • Individuals (16) • Sale of services (2) • Membership dues (3) • Other (2)
Who is responsible for fundraising?	• Director = 11 • Accountant = 3 • No response = 17

Do you have the minimum funds necessary to ensure the association's stability (keep office, maintain minimum staff and activities)?	Yes = 17 No = 8 No response = 6
How would you characterize your sustainability over the next 2-3 years?	In response to this question, organizations listed legal status, active members and stable office space as elements of sustainability. No one offered a projection for the future.

4. Main activities and programs	
Direct support to children: How many children are involved in each type of program?	• School preparation (18) • After-school tutoring (10) • Therapy (occupational / physical) (6) • Counseling (9) • Registering for pensions (19) • Enrolling in KG / school (0) • Other (0)
What materials and modules do you use for your programs? If they are international how have you adapted them?	Adapted international material (11) Concept on Inclusive Education (1) Official policy documents (2)
Parent Support	• Legal / Advocacy (21) • Counseling / Self-help (20) • Information (about disability) (18) • Workshops / Seminars (21) • Other (2)
Do you have programs on inclusive education? If so, which schools work with you and how many children attend?	Yes = 13 No = 7 No response = 11

Other programs	• Education (classes or group work w/ children) (11) • Advocacy / public information (10) • Campaigns (12) • Other (4)
What does your association do best? What is your most important activity?	• Our children can act as disability ambassadors: 1 • Our children know their rights: 1 • Working with other associations: 2 • Inclusive education: 9 • Support for families of CWD: 11 • Working with children directly: 2 • Raise awareness about disability: 6
Ideas for the future – what programs or areas of expertise would you like to develop?	• School preparation (23) • After-school tutoring (13) • Physical therapy (15) • Occupational therapy (10) • Legal / Advocacy (20) • Education (classes or group work w/ children) (17) • Public information / Media (18) • Counseling / Self-help (22) • Information (about disability) (19) • Other: (5) exchange experience with other groups in Central Asia (1); early intervention (1)

5. Participation in the Coalition	
How do you understand the structure of the Coalition?	• Strong (12) • Adequate (14) • Weak (0) • No response (5)
How often do you contact other members?	• Once a week (13) • Once a month (14) • Once in 2-4 months (6) • Once in 6 months (0) • No response (0)

Where is the nearest member organization?	• In this town (7) • Less than 10 km away (4) • Less than 30 km away (4) • Less than 50 km away (2) • 50 km or more (9)
How do you contact other members of the Coalition?	• Telephone (26) • E-mail (19) • Informal meetings / Visits (12) • Formal meetings (14) • Other (2)
What do you usually discuss? What are the questions or activities that you have in common?	Daily challenges of parent associations: 6 Current or future projects: 12 Current activities of the Coalition: 8 Personal problems: 1 Exchange experience: 5
Why are you a member of the Coalition? What do you get from this?	Support developing project and fundraising: 3 Exchange of professional experience: 14 Partnership: 5 Inclusive education programs: 1 National advocacy: 1
What do you contribute to the Coalition? Is there something else that you would like to contribute?	Provide support for other associations: 5 Writing joint project proposals: 1 Hire members of other APDCs as trainers: 1 Personal professional experience: 6 Local implementation of Coalition plans: 7

What suggestions do you have for the development of the Coalition?	Site visits and exchanges with other APDCs: 8 Study visits in other countries of Central Asia: 2 Equal partnership and support for common ideas: 4 Regional partnership: 1 More partnership projects: 4
What should the Coalition plan to do in the future?	Support inclusive education: 3 Defend the rights of CWD: 1 Learn about parent organizations in other countries: 2 Partnership with state structures: 5 Register as a Union of APDCs: 4 Bring more organizations into the Coalition: 7 Work with media: 1 Advocacy for better laws & CRPD: 1

Note: Questions indicated in red were added at the request of OSI Tajikistan. They used this questionnaire for a general survey of all Coalition members on May 6, 2015 during a general meeting in Dushanbe. All 31 associations and initiative groups participated.

Appendix 10: Code Book

Codes for basic demographic information			**Codes of interview responses**	
Check box			Method of joining the association	JOIN
Checked	1		founding member	1
No response	0		word-of-mouth or referral	2
			outreach from the association	3
Interview site			sought out after event or media information	4
Dushanbe	1			
Bokhtar	2		When learned of disability	TIME
Khujand	3		At birth	1
Kulob	4		Infancy	2
Khorog	5		Toddler or older child	3
Murghab	6		Acquired disability	4
Language			Family support	FAM
Tajik	1		Own mother	1
Russian	2		Husband	2
Uzbek	3		Sibling	3
Tajik/Russian	4		Other	4
Russian/Tajik	5			
Tajik/Uzbek	6		Negative family reactions	NEG
Uzbek/Tajik	7		Mother- or Father-in-law	1
Russian/Uzbek	8		Husband	2
Pamiri	9		Extended family	3
Kyrgyz	10			
			Experiences in healthcare	MED
Place of birth			Offered institutionalization	1
Dushanbe	1		Offered euthanasia	2

Khujand	2		Disability defined in hopeless terms	3
KT	3		Difficulty identifying disability	4
Kulob	4		Given misinformation	5
Khorog	5		Unkind or discriminatory behavior of healthcare workers	6
District center (Soghd)	6			
District center (Khatlon)	7		Benefits of membership in the association	BEN
District center (RRS)	8		Shared experience - mutual understanding	1
District center (GBAO)	9		Information sharing	2
Uzbekistan	10		Improved access to expertise	3
Russia (small city)	11		Provision of services	4
Turkmenistan	12		Material support (job, money, childcare)	5
Rural town (Soghd)	13			
Rural town (Khatlon)	14			
Gender				
Male	1			
Female	2			
Education			Disability type	
Basic	1		Down Syndrome	1
Secondary	2		Cerebral Palsy (CP)	2
Prof. Secondary	3		Autism	3
University	4		Deaf/hearing impaired	4
No Education	5		Blind/visual impairment	5
			Physical disability	6
Relationship to CwD			Developmental or intellectual	7
Parent	1		Speech impairment	8
Grandparent	2		Epilepsy or seizures	9
Other family	3			
			Profession	
Head of household (in relation to the respondent)			Teacher / education	1
Husband	1		Doctor / healthcare	2
Father-in-law	2		Lawyer	3

Father	3		Law enforcement	4
Son	4		Construction / factory labor	5
Mother-in-law	5		Driver	6
Mother	6		Farmer	7
Self	7		Business / management	8
			Skilled trade	9
Father lives nearby			Other professional	10
Deceased	1		Housewife	11
No	2			
Yes	3		Marital status	
Living, unclear residence	4		Married	1
			Divorced	2
			Widow/ widower	3

Vita

Kate Lapham is the deputy director of the Education Support Program of the Open Society Foundations. Her work focuses on overcoming barriers to education for communities facing exclusion or discrimination. Based in New York, Lapham has worked with communities, civil society groups, and education policymakers in Eurasia, Eastern Europe, and Mongolia for more than 20 years. She joined the Open Society Education Support Program from IREX, a nonprofit organization dedicated to quality education, independent media, and strong civil society.

Lapham has developed initiatives to strengthen civil society through exploration of common interests and challenges, including research for evidence-based advocacy, support for organizational development among start-up NGOs, and direct work with teachers and schools. She leads the Education Support Program's grant making in support of the right to education in fully inclusive settings. Her publications include *Learning to See Invisible Children: Inclusion of Children with Disabilities in Central Asia* and "Including Children with Disabilities in Tajikistan's Education System: Global Ideas, Local Tensions" in *Globalization on the Margins*.

Lapham holds an MPA from Columbia University's School of International and Public Affairs and a BS in foreign service from Georgetown University.

The End